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ABSTRACT

This document gives parents, teachers, and others basic information and suggested guidelines for teaching children aged 10 and younger about Acquired Immune Deficiency Syndrome (AIDS). These topics concerning AIDS and young children are discussed: (1) talking with young children about AIDS; (2) things to keep in mind when talking with children, including the relationship with the child and the child's age and developmental level; (3) appropriate times to bring up the topic of AIDS; (4) questions children may ask about AIDS and how to answer them; (5) guidelines to keep in mind when talking to children when a child, family, or friends are at risk or are infected with the AIDS virus; (6) issues for the young child in foster care; (7) AIDS education in the early elementary classroom; (8) anticipating problems that might come up in discussing AIDS with young children; and (9) guidelines for the school with human immunodeficiency virus (HIV) infected students or staff, including informing teachers, parents, students, and the community at large. Descriptive information about AIDS is provided, including epidemiology, symptoms of infection, and prevention and testing. Advice is given on how to stay updated on AIDS information. AIDS information appropriate for infants, toddlers, early childhood, and school-aged children is given. Physical and behavioral/attitudinal signs of sexual abuse are listed. Further resources of AIDS are listed, including written materials and organizations. (ABL)

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"DOES AIDS HURT?"

EDUCATING YOUNG CHILDREN ABOUT AIDS

CG 021315

Marcia Quackenbush, MS
Sylvia Villarreal, MD

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
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TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Suggestions for teachers, parents and other care providers of children to age 10

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EDUCATING YOUNG CHILDREN ABOUT AIDS

Marcia Quackenbush, MS
Sylvia Villarreal, MD

Suggestions for parents, teachers and other care providers of children to age 10

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Preface

Over the months that we have spent writing this book, we have heard two typical reactions from people who hear about our work. One is, "I'm so glad you're doing this. A book like this is really needed. A lot of people will be looking forward to reading it." The other is, "Do you really think a book like this is necessary? Why would anyone want to talk about AIDS with young children? Don't children already have enough to worry about?"

We agree that children today have a lot on their minds, and they certainly don't need new things to fear. We also know that some children *do* have concerns about AIDS—they are afraid they might catch it, or that their parents might. They may have heard about children with AIDS who have been abandoned or mistreated. They may have picked up some confusing (and perhaps inaccurate) information about AIDS and sexuality or drug use from schoolmates. As this epidemic spreads and affects greater numbers in this country, more children across the nation are likely to have these concerns.

The best reason for writing this book is to support parents, teachers and others in guiding children through life with one less fear. We are trying to accomplish the delicate task of offering children hope in a world that has no guarantees. Helping children understand AIDS in a productive and useful manner, appropriate to their age, is one of many challenges we face in our endeavors. We hope this book will prove useful to others facing this challenge in the years ahead.

We dedicate this book to children, who are our future.

Notes to the Reader

1. A number of vignettes are included in this book. We have changed the names and some of the identifying information in these stories to protect the confidentiality of the persons involved.

2. In the text of this book, we refer to AIDS and also to the broader syndromes of ARC (AIDS-Related Complex) and HIV infection. HIV is the name for the virus that causes AIDS, and anyone infected with this virus, whether or not symptoms are present, is said to have HIV infection. Persons with ARC have symptoms of HIV infection, but do not meet the necessary criteria for an AIDS diagnosis.

   For young children, it will often not be necessary to make the distinctions between AIDS, ARC and HIV infection. We need to keep our explanations as simple as possible. We feel it is acceptable to sacrifice some points of scientific accuracy so we may better clarify more general and essential concepts to young children.

3. When we refer to "young children" in this book, we are speaking of children up to age ten.

SECTION 1

AIDS AND YOUNG CHILDREN

Chapter 1

Talking With Young Children About AIDS

Helen never expected that she would need to talk about AIDS with her students. As a third grade teacher in a small, fairly conservative town, it did not seem like a very pressing issue. Her students had never expressed any interest in the topic, and she did not think their parents would want her to teach on the matter.

The whole town was shaken when the adult son of one family, a man who had left town after high school graduation, returned with a diagnosis of AIDS. He would be living with his parents, who would help care for him and support him. There were conflicts in the community about this man—some were glad he could return for support, while others wished he had never come back.

Helen began to see these conflicts played out among the students at her school. She also saw some children become anxious about "catching" AIDS, others repeat cruel or crude jokes, and others share misinformation among themselves. She joined a few teachers who suggested developing classroom lessons addressing these issues. Controversy flamed again, with some townspeople supporting the idea and others vociferously against it.

"Ultimately, of course, it was the children who suffered," she told us. "We never thought our town would be touched by this epidemic, so we

didn't prepare ourselves well. By the time we did address the issue, we were in a crisis. There was no time to educate people, to help them better understand the need to teach their children about AIDS. The children were totally confused by the different things they heard from one another and their parents."

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AIDS brings up many difficult issues—life and death, illness and disability, intravenous drug use, human sexuality and homosexuality. Many adults find it uncomfortable to discuss these topics among themselves. It is understandable that one might wonder why anyone would want to bring up such sophisticated material with young children. It is our purpose to explain that there *are* important reasons to talk with young children about AIDS, and to share some suggestions for just how to do this.

One thing we want to make immediately clear is that we are not suggesting children be presented material that is beyond their understanding. We believe children deserve good and appropriate answers to their questions, and many *do* have questions about AIDS. However, "AIDS education" for many young children will not need to be explicit or even very specific, and in most instances it will really have more to do with health and communicable diseases generally than with AIDS particularly. By laying a careful foundation of understanding, we can prepare young children for more sophisticated explanations of AIDS and other health issues in later years.

AIDS is becoming a bigger part of American life. Internationally, it is a major health problem. The ultimate effects of this epidemic on our social system, our global economic system, our world health system, and our individual lives cannot fully be imagined at present. An issue as big as AIDS will touch the awareness of children of all ages, whether or not they are told about it directly by their parents or teachers. On television and the radio, in conversations of adults around them, in playground interactions with peers and with older children, in the newspaper as they begin to read—children hear about AIDS.

And since they hear about it, children also have questions about AIDS. This is only natural. Children are fascinated by the world around them. They might wonder why it turns dark at night, how a television works, or why they bleed if they cut themselves. As children grow, they discover that accurate answers

to questions can sometimes make their lives more familiar, more exciting and more comfortable. Now that AIDS is a part of our world, we find that even very young children are beginning to ask questions about the disease.

In the same way that it is natural for children to ask questions, adults who care for them—their parents, teachers, health care providers and other caretakers—want to give them accurate and age-appropriate answers. With a topic like AIDS, this wish to teach children about the world is complicated by the difficulty of the subject. Just what is an "age-appropriate" response to a young child's questions about AIDS? When, if ever, should adults initiate a discussion on the topic? What do children want to know, and what do they need to know?

This book has been written to help parents, teachers and others who spend time with children develop answers to these questions. The recommendations we make are based on our personal experiences with children and interviews with parents and professionals who work with children. There are few absolutes in this matter—each child and each community are different, and what is useful in one place may not be in another. We hope the suggestions in this book can be used as a frame of reference to help parents, teachers and other caretakers answer children's questions.

We want to emphasize the importance of the phrase "age-appropriate material." Often when we talk about providing AIDS education to young children, people assume this to mean that we want to talk to six year olds about topics like explicit sex. This is far from what we recommend. Appropriate material for a six year old would include some basic concepts about health and communicable diseases (they exist, some are easy to get, some are hard to get). This information should be presented in the context of a comprehensive school health program, and taught by the regular classroom teacher. AIDS might not be mentioned at all, or might be referred to only in passing. If a child this young is bringing up questions about vaginal, oral or anal sex, one would want to consider carefully the possibility that this child, or one of his or her friends, was being sexually molested. Most six year olds neither need nor want graphic descriptions of adult sexual activities.

We also acknowledge the limitations of this book. It is not a comprehensive guide to teaching children about health and sexuality; it is not a comprehensive source of information about AIDS; it does not provide a comprehensive description of child development. We summarize each of these topics and

relate them to our subject, but for thorough background in any of these areas, we refer you to one of the resources listed in Section 3 of this book.

Why Do Young Children Need to Know About AIDS?

There are a number of good reasons to learn to talk to young children about AIDS. Some apply to all children and some to only a few, but together we think they create a compelling rationale. We list our reasons below.

1. The natural curiosity of children.

As we already mentioned, children are naturally curious about the world around them. AIDS is now, tragically, an undeniable part of that world. Young children will and do have questions about AIDS.

This curiosity is a healthy and delightful quality of children. Responding in a positive and appropriate way to their questions encourages healthy and vigorous development of their cognitive, social and emotional skills. In this sense, AIDS is no different from all the other subjects that fascinate a child.

If we neglect or refuse to answer these questions, we frustrate a child's wish to know about the world. He or she may begin to feel less interested and less motivated to learn, or may feel ashamed or guilty about being curious. When our reticence to respond extends only to certain topics—like AIDS, or sex, or death, or a family member's obvious but unaddressed trouble with alcohol—the child usually learns to avoid these areas of questioning. He or she will seek answers from other sources. The information may be inaccurate, and it may endorse values inconsistent with those of the parents.

2. The anxiety children may have about the disease.

Children understand that AIDS is a very serious disease. They usually do not understand the concept "not casually transmitted." They have caught colds and chicken pox easily in the past. What can protect them from catching this very serious disease in the future?

In addition to their personal fears of contracting AIDS, young children may worry that parents or other family members will become ill. This concern is especially challenging when parents or other family members *are* actually at risk,

or are practicing risky behaviors. Giving children tools to understand concepts about disease transmission can help lower this kind of anxiety.

3. Some children may have parents, other family or friends with AIDS or HIV infection. These children will benefit from the presence of compassion and understanding among their peers.

Children who have a family member diagnosed with AIDS or HIV infection face many personal challenges. We do not want to add the harassment or misunderstanding of peers to an already painful circumstance. When children feel secure that AIDS is not casually transmitted, and when they have seen teachers and parents model humane responses to those who are ill (or who have illness in their families), they are less likely to tease or criticize someone in this situation.

4. Many communities, schools and neighborhoods will be home to HIV-infected children and adults in the future.

AIDS education can lay a groundwork to help both children and parents avoid harmful or negative reactions in these instances. When communities become distraught over the presence of HIV-infected children, this is obviously a difficulty for that child and his or her family. However, the divisiveness and bitterness that have arisen in some cases hurt the greater community as well. No one is served by overly emotional responses, and we are all helped by clear and accurate information.

Comprehensive School Health Programs

AIDS presents one of the biggest challenges parents and educators have ever faced—that of helping to save the lives of their children and students. Young children need help developing a conceptual framework about health and communicable disease that will lead them to a fuller understanding of AIDS in later years. Much of the education they need in this light is not specific to AIDS at all, but addresses broader issues of wellness and illness; understanding communicable diseases and their prevention; being familiar with common health practices that help stop the spread of disease in general; and developing

the awareness that those who are ill need compassion and support from the community and good medical care from their health providers.

In a school setting, these matters most naturally fit into a comprehensive school health program. Such programs seek to promote health education that addresses the whole child—mentally, physically and socially. Planned instruction focuses on health-related topics for students in grades K-12, with increasing sophistication as the child matures. From such programs, we hope, each child will develop behaviors that enhance personal health and well-being, while avoiding behaviors that might cause disease or health problems. We want children to learn to look beyond their own personal interests and think also about the health and well-being of their family, their friends and the larger community. Finally, we want students to think about the well-being of future generations.

The AIDS epidemic makes it clear as never before that comprehensive school health programs are essential to the well-being of our nation's children. Health education must equip children with fundamental concepts and personal skills to protect and enhance their own health and that of the community. These concepts and skills will not magically appear in young people at whatever age they are first given the opportunity to engage in sexual activity or drug use. The abilities to make sound decisions for one's health and well-being, to resist peer pressure, to feel positive about oneself, to refuse invitations to engage in non-healthful activities, are skills that can only be built over time, in a carefully sequenced manner that builds new understanding on previous material and includes a lot of practice.

When we start programs early—teaching young children about such topics as what good hygiene is and why it is important, some of the ways diseases are passed, and how to protect oneself from illness—we are building that essential foundation. In addition, we find that when such programs are in place, and particularly when they are reinforced with parent involvement (through parent review of materials, providing informational meetings for parents, parent participation in some student homework assignments, and so forth), answers to children's questions about AIDS come much easier for parents, teachers and others who work with children.

Additional AIDS Prevention Strategies For Young Children

In addition to the knowledge we want young children to have about health, disease, and AIDS, there are two important AIDS prevention strategies to consider for this age group.

1. Children face a small but real risk of infection through sexual molestation by an HIV-infected adult.

Horrible as it is to imagine, such cases have occurred. We need to do all we can to prevent any child in our care from facing similar traumas. Adults should act swiftly and aggressively to protect the child in cases of molestation. Programs that teach children skills to avoid sexual abuse should be supported. These lessons should be included within a comprehensive school health program. (See Section 3, *Further Resources,* for references on this topic).

2. Drug use is associated with HIV infection. Within the health program, drug prevention programs should be started in early elementary grades.

The best way to prevent drug abuse is to teach drug prevention lessons early and repeat the messages over time. The best drug abuse prevention programs are a sequenced and planned part of the school's health education program. Support for these programs also promotes AIDS prevention.

Keeping Parents Involved

The role of parents in educating young children about health issues is essential and cannot be overemphasized. Parents are the primary educators of children about morals and values, personal relationships, sexuality and self-esteem. What the child sees in practice in the home is what he or she learns to generalize to the rest of the world. School-based lessons in these areas are not especially useful if they do not relate to the values the child learns in the home.

This is one reason it is so important for parents to be involved in the development and/or evaluation of curricula on such topics. We believe parents

should have the opportunity to review any school materials, to provide input, and to observe classes. Ideally, parents will see themselves working in partnership with the schools.

It is important that the entire school curriculum be consistent with children's cultural, religious and ethnic background. This is particularly essential for lessons about AIDS, drug use and abuse and human sexuality. In our multicultural American society, community input and parent involvement are especially important. We believe the local community will have the best understanding of how to educate children, and suggest that there be careful local review of any materials to be used in group settings with children.

Many successful lessons concerning health and personal relationships involve homework assignments during which children discuss the lessons with their parents. These discussions create an atmosphere of openness and honesty, which contributes to better learning for the student while reinforcing the values of the family. These kinds of models are appropriate for AIDS education as well. We hope that parents will take an active role in educating their children and promoting good comprehensive health education programs in their community's schools.

Talking About AIDS: What Do You Need to Know?

Many parents and others who care for the young wonder how to prepare themselves to talk about AIDS with children. It may seem a little intimidating—there is so much information about AIDS; the related issues are sensitive and complicated; it is often uncomfortable to talk about these topics; and teachers may worry that parents will be upset if they hear that these subjects have been addressed with their children.

It is important to remember that, though AIDS is a new disease, most of what it brings to light is not new. Children have always asked questions about health and illness, life and death, intimacy and sexuality. Parents and teachers already have ways they handle sensitive issues when they arise. In learning to talk with young children about AIDS, we are primarily using communication and teaching skills that have been used in other circumstances before. We adapt these approaches to the particular facts about AIDS.

To be comfortable with this task, you will want to have a general familiarity with the following areas, all of which are covered in this book:

1. **Child development.**
   How and what do children think about health, personal relationships and sexuality? What kinds of questions will they have on these topics? This material is covered in Chapter 12: *AIDS Information and Developmental Stages: What Do Children Want to Know about AIDS, When?*

2. **Basic AIDS information.**
   Accurate answers are based on a sound general knowledge about transmission, prevention and the course of the disease. Very sophisticated knowledge is not necessary—young children cannot understand more than the most basic information. A good basic information resource is Chapter 11: *AIDS Information: Answers for Adults.*

3. **Some idea of the sorts of questions young children are asking about AIDS.**
   This is explored in Chapter 4: *What Are Children Asking, and How Can You Answer Them?*

4. **Ideas about how to answer these questions, or otherwise bring up the topic of AIDS appropriately with children.**
   These concerns are covered in Chapter 3: *When Should You Bring Up the Topic of AIDS?*, Chapter 4: *What Are Children Asking, and How Can You Answer Them?*, Chapter 5: *Special Circumstances: When a Child, Family or Friends are at Risk for or Infected with the AIDS Virus,* and Chapter 6: *Issues for the Young Child In Foster Care.*

Four Important Values When Providing AIDS Information

There are four basic values that we hope will underlie all approaches to talking with children about AIDS.

1. Persons with AIDS/HIV infection, and their friends and relatives, should be considered with respect and compassion.
2. We do not want to speak in a manner that would lead children to feel badly about themselves or negatively about human sexuality and intimacy.
3. Most people, including children, have sexual feelings, and this is quite natural. However, sexual activities like intercourse are not appropriate for children.
4. Curiosity is natural and questions are healthy. We want children to ask these questions and especially encourage them to discuss their thoughts with their parents.

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As you review and consider the information in this book, we hope you will remember that the most essential skills for talking about these matters with children cannot be taught in this or any other resource. Openness, expressions of love and caring, willingness to be honest and genuine—these are qualities most parents, teachers and others who care for children cultivate, and these are the qualities that will make your time with children more rewarding and your teaching of them most effective. Listening carefully to children, allowing them to complete their thoughts and questions before offering answers, and checking their understanding of the discussion will facilitate talks about AIDS or other sensitive issues that are productive and helpful.

Chapter 2

Things to Keep in Mind

"I know you are writing a book about how to talk to young children about AIDS, and I wanted to tell you about an experience I had," our friend Ernesto said. This is what he told us:

My parents were visiting, and my five-year-old son and I were taking them on a tour of the city in the car. My boy was in the back seat and seemed totally involved in playing with a few toys he had brought along, so I assumed he wasn't listening to the grown-ups talk.

As we drove through the gay neighborhood, I commented that things had really changed there since the AIDS thing happened—there were a lot fewer people around, there was a mood of depression, and I guessed it was because so many of them had died. My son suddenly pipes up, "They died? *Why did they die?"*

"Oh, they caught a disease," I said. But he's the kind of kid who has a lot *of questions when his curiosity gets started.*

"What disease?" he asked me.

"It's called AIDS," I answered.

"How do people get it?" he asked—of course! I could tell my parents were beginning to feel uncomfortable with this. They aren't the kind of folks who ever had a lot of explicit talks with their children. So I tried to answer his questions, but I was getting nervous about what my parents

were thinking, and my son kept asking harder and harder questions—"Why did people in this neighborhood get it?" "Aren't these gay men? What makes them gay men?"

Finally I told him it would be better if we could discuss this later because it was a hard subject for me to explain to him. Usually I wouldn't do that, but I was so distracted by my parents' presence, I didn't feel like I was doing a very good job answering his questions anyway.

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There can be few absolutes when we make suggestions about how to answer young children's questions about AIDS. We give some specific examples in Chapter 4: *What Are Children Asking, and How Can You Answer Them?,* and Chapter 5: *Special Circumstances: When a Child, Family or Friends are at Risk for or Infected with the AIDS Virus,* but your own approach to educating children about AIDS will depend on many different things, including:

1. **Your relationship with the child.**
   Is this your own child? A student in the classroom? A patient? A child of a neighbor?

2. **The particular circumstances at hand.**
   Are you speaking privately with the child, or in a large group? Do you have a lot of time or are you "on your way out the door"?

3. **Your own sense of preparedness.**
   Have you been surprised by a sudden question? Are you bringing up an issue you had planned to talk about?

4. **Your previous discussions with the child on this or related topics.**
   Do you have a comfortable foundation for talking about this issue, or is it something new for both you and the child?

5. **The child's age and developmental level.**

6. **Any special history pertinent to the circumstances.**

Has the child just been frightened by a news broadcast? Is someone close to the child ill with HIV infection?

7. If the child is asking a question, what is the real meaning behind the question?

These are a lot of variables to keep in mind! It makes this task seem so difficult. But if you look over the list once again, you will see that, in fact, these are the kinds of things adults always attend to when educating children or responding to their questions. Once again, the skills that have served parents, teachers and others well in their contact with children in the past are those that will be most useful in addressing this new issue of AIDS.

Four Goals for Parents, Teachers and Caretakers

Most of us cannot keep in mind at all times all the specific suggestions and facts about discussing AIDS with young children. It may be useful to remember four general goals.

1. Parents and caretakers can set a groundwork for communicating about health, human loving, sexuality and values from a child's earliest age. Teachers and other educators can set a foundation for young children to understand health and communicable disease and, as appropriate, human sexuality (considering the child's age, school guidelines, community values and the specific circumstances).
2. Those who care for children can help the child develop a confident and strong sense of self and of being loved.
3. Adults can demonstrate a willingness to answer children's questions about AIDS as they arise. They can also explore the meaning behind the questions to try best to help the child cope with anxieties or feel that his or her concern has been addressed.
4. Adults who care for children can demonstrate a willingness to bring up the issue of AIDS with young children at times when it is appropriate to do so.

Teaching Children About Sexuality

We suggest that parents and, as appropriate, teachers, health providers and others working with children respond to children's natural questions about sexuality as they arise. If children are not asking these kinds of questions (about reproduction, anatomy, growth and development and sexual feelings), we hope parents will initiate conversations on these topics. It is important that a child have a basic knowledge of human sexuality to be able to understand some of the answers to his or her questions about AIDS. More essentially, we want children to have a positive sense of human sexuality as a unique activity between people who care for each other in a very special way, and we want them to develop a positive and comfortable sense of their own sexuality as they grow. If they hear about sexuality first in the context of AIDS, they will be associating this wonderful element of life with a frightening disease, and with death.

We discuss some of the particular interests of young children concerning health and sexuality in Chapter 12: *AIDS Information and Developmental Stages: What Do Children Want To Know about AIDS, When?*, and give some examples of answers to some questions about sexuality in Chapter 4: *What Are Children Asking, And How Can You Answer Them?* We hope parents wanting more guidance in this area will refer to the "Further Resources" section.

Give Yourself Some Leeway! Basic Guidelines

It might be helpful to start by setting a few ground rules for yourself. We suggest some here, and you may add others that are important to you.

1. You do not need to know all the answers.

AIDS is a big topic, and it touches on other challenging issues. While you will want to give children the clearest answers possible, they may ask for information you do not have. If there is some piece of information about AIDS you need, you can research the answer and get back to the child. Other questions may be of a more philosophical nature ("Why are some people so mean to

someone who has AIDS?"), and it is okay to admit that these things are hard for grown-ups to understand too.

2. You can take a short time out.

If a child surprises you with a difficult question, you can take a moment to think about your answer. You might say something like, "That's a good question. I need to think for a moment about how I can explain some of these grown-up things in a way you can understand." Be sure you *do* answer the question as best as you can after a moment.

3. You can make mistakes.

Unless you have a *lot* of experience talking about sensitive issues with young children, you will have second thoughts about some of your answers. Hindsight often reveals many new possibilities and approaches to your responses. If you have an ongoing dialogue with a child, you can give a better or more careful answer at another time. We will get more expert at this as we practice. Children are resilient enough to recover from our clumsiness if we continue our endeavors to teach them well.

The Meaning Behind the Question

Another thing to keep in mind is what a child really wants to find out when a question about AIDS comes up. It may be helpful to think of different categories of AIDS-related questions that arise with young children. We outline below some categories to consider.

1. Information-seeking and general curiosity.

These questions from children are fairly straightforward. The child's curiosity is stimulated in some way and there is a natural interest in finding out more. This might include questions like: "What is AIDS?" "How come gay men get AIDS?" "How do people get AIDS?" You might also hear questions that are less fearful and more philosophical in nature: "Why do people die?" "Why does God let babies get AIDS?" We sense a different quality in these sorts of questions, but young children may expect factual answers to such queries as

well. If we answer: "I don't really know myself," they often believe we know answers but are withholding them for some reason. Certainly, one of the lessons we must all learn with AIDS is that there is much in life we cannot well understand.

2. Anxiety for one's own welfare.

Many children are frightened by the things they hear about AIDS. They might hear a newscast about a five year old with AIDS, and somewhere else they have heard that people die of the disease and there is no cure. They wonder if they could get it, or if they will die. A question like: "How do people get AIDS?" may fall into this category as well. Children might also ask: "Will I get AIDS?" "How do children get AIDS?" "What kind of people get AIDS?" "Are people with AIDS bad?" "Can you get AIDS from kissing?," all with the intent of discovering whether they are at risk themselves.

3. Anxiety for the welfare of parents, siblings or other family, and friends.

Family is tremendously important to the young child, and many children might worry about their family's risk for AIDS. They hear that people get AIDS by having sex or using drugs, and perhaps they know that their parents have sex or use alcohol, marijuana and other drugs. This can be very alarming to children, and in some cases the parents may actually be engaging in AIDS risk behaviors.

These kinds of questions might be quite direct: "Mommy, do you think you will get AIDS?" Or, to a teacher: "Will my mother get AIDS?" Some may be more general: "Will everyone get AIDS?" "Do all grown-ups know how not to get AIDS?" "Is it easier for grown-ups to get AIDS than children?" "Is it okay for my daddy to have sex?"

4. Solution seeking.

By the time children are seven or eight, they often like working puzzles or solving problems. They may try to come up with solutions to the problems raised by AIDS. "Could a very good doctor help someone with AIDS be healthy?" "Can we give someone with AIDS new blood to help them be better?" "If we give children with AIDS lots of grow-food, can they be strong and healthy just like me?"

5. Seeking reactions from adults.

It *is* hard to talk about AIDS, and sometimes children, sensing this, will bring the topic up to see how adults react. Children may enjoy baffling the know-it-all grown-ups in their lives with embarrassing or difficult questions. If an adult answers these sorts of questions in an honest, matter-of-fact way, children will soon lose interest in the game. Meanwhile, they may have discovered a good resource of information for a future time when they have a more serious question to ask.

6. Special psychological needs.

Some children may be unusually anxious, and AIDS can become the focus of anxiety for these children. Such a child may ask identical or similar questions about AIDS over and over again, never seeming satisfied with the answers and never absorbing the information. If such questioning is unusual in its intensity and persists over a period of time (several weeks), a consultation with a child counselor may be called for.

When children do ask questions about AIDS, remember to consider the meaning behind the question. The same words can ask many different things. If a straightforward informational response does not seem to satisfy a child, you might ask about some of his or her own thoughts on the matter to try to get a better understanding of the child's concern. Please also remember that in some instances children may be victims of sexual abuse, and that AIDS information may bring up special anxieties for the abused child. Be familiar with signs and symptoms of childhood sexual abuse and how to proceed to protect a child if you have reasonable evidence that such abuse is happening. (See Chapter 13: *Signs of Child Sexual Abuse,* for more information.)

Chapter 3

When Should You Bring Up the Topic?

There will be instances where it is appropriate to bring up the topic of AIDS with young children. In some cases, this will be a task for parents; in others it will be a responsibility of teachers or schools. In most of these circumstances, this will be a carefully considered and planned activity.

Usually, children of about four years and younger will not bring up the topic of AIDS themselves, nor will they have the capacity to understand it well. Except in situations where it is clear a child this young needs some help understanding something about the disease (for example, if a parent or other close relative is quite ill with HIV infection), we think adults will not need to initiate discussions about AIDS with children this age.

After this, parents may want to consider bringing up the topic of AIDS in a number of circumstances. Certainly this will depend on the interest or maturity of the child, and since children mature at different rates this will be different for each child. We do know that children may be hearing about AIDS from classmates or older children in school settings. Much of what they hear may be incorrect, may be inconsistent with parental values, or may provoke anxiety in the child.

We hope that parents will look for opportunities to mention AIDS when they feel their children have the maturity to understand the discussion. This could involve a general conversation about related topics—perhaps health, sexuality,

or things that frighten people. Such talks give parents an ideal opportunity to reinforce family values concerning compassion, death, sexuality, substance abuse and so on. Then, when the child hears about AIDS from other sources, there will be a frame of reference that will help him or her understand the information more comprehensively, and in the context of family values.

For example, a child may be nearby when a news item about AIDS is broadcast on television. A parent could use this opportunity to check with the child about levels of anxiety and understanding—"Here's another story on the news about AIDS. I wonder if you ever think about AIDS, or if you have any questions about the disease." In a short conversation, the parent can see if there *are* further questions from the child. The parent also demonstrates a willingness and openness to address AIDS and other interesting issues at any time the child wishes to do so.

In the same way that children overhear adults' conversations, adults may overhear children talking with playmates about any number of topics. If a child is talking about AIDS, listen carefully to the information and to the tenor of the conversation. Does the child seem anxious or afraid? Is the information factual, or are there troublesome inaccuracies? When children simply discuss AIDS in the course of their day, it is of no special concern. Where there is anxiety or significant misinformation, however, an adult will probably want to bring this up with the child at that time or soon after. The primary goal will be to lower anxiety. Clarifying misinformation is a second goal.

Some children have parents, family members or friends who are known to be HIV-infected. For these children, it is important to maintain open communication about their concerns. If this parent or friend is not seriously ill (with a frank diagnosis of AIDS or significant symptoms of ARC), it is probably not necessary to share in-depth details with the child. However, if a child overhears parents or other adults reacting with sadness or grave concern, some follow-up may be called for. Finally, in cases where the individual is ill, children touched in some way by the illness would benefit from a clear conversation with a parent or other appropriate adult.

In these discussions, we think adults should combine honesty and hopefulness as much as possible. We do not want children to feel unnecessarily burdened; neither do we want to misrepresent the situation. "Yes," you might say, "we are very concerned about John's health. AIDS (or ARC), the disease he

has, is quite serious. We are hoping he will stay strong until the doctors can figure out how to make him better." If the person is in a grave and perhaps terminal decline, it would be appropriate to bring up the possibility of his or her death. Death, like sexuality, is easier to talk about with children on an ongoing basis. If a foundation has been set, the discussion will follow fairly smoothly. In these sorts of talks, remember to invite children to ask any other questions they may have.

In other cases, some children may worry that family or friends have a risk for HIV infection. This can raise tremendous concern for the child. If a caretaking adult hears a child express such a belief, it would be appropriate to explore the child's worries further. "I wonder why you think your older brother might get AIDS?" Listen carefully to the answer. Does the child have incorrect information about HIV transmission? Is there a real risk? Or, as is often the case, is it difficult to determine from the child's answer? (An answer like, "People get AIDS from using drugs and my brother uses drugs," is ambiguous. What kind of drugs is the brother using? How real is the risk?)

It is important for children to see that the adults (and other older role models) around them take good care of themselves. This not only models self-care and self-esteem for the child, but it also reassures the child that the important grown-ups in his or her life have a commitment to stay healthy so they can continue to provide care. The young child's physical survival depends on the presence of parents or other caretaking adults, so a threat to someone close is a threat to the child him or herself.

In these instances, we hope we can confidently assure the child that the individual *does* know about AIDS and how to prevent transmission, and will act to protect him or herself. In some families, it might be possible to have an open discussion with the brother (or friend or uncle or whomever) and actually demonstrate to the child that this person *has* been educated. One can also help the child understand important distinctions about AIDS transmission—on the one hand, sharing needles in drug use specifically provides the virus an opportunity to infect someone, and intercourse with an infected person poses a risk; and, on the other hand, a mutually monogamous relationship between two uninfected people poses no risk.

The more challenging circumstance arises when a child perceives a risk to someone and it seems the perception may be accurate. Some grown-ups do not

take care of themselves, and they do engage in behaviors that put them at risk for HIV infection. This is not a situation that can be resolved for the child through "education." The conflict for a child in such circumstances is not about AIDS, per se, but about caring for someone who does not care well for him or herself. Support and empathy are called for, along with acknowledgment of the validity of the child's concerns, and reassurances that the child is not responsible for the situation. If intervention services (e.g., drug detoxification programs) are available to help the adult in question, using them may improve the situation. If a parent is the object of concern, family counseling may help. Individual therapy for the child might also be considered.

The final circumstance in which we feel adults should certainly initiate discussions about AIDS with young children is when an HIV-infected child is known to be attending the children's school, or in cases in which it becomes known that a school employee is HIV-infected. This calls for group discussions with children in classroom settings, based on careful planning by school administrations and involving parents.

We discuss several of these circumstances in later chapters. You can especially check Chapter 5: *When a Child, Family or Friends Are at Risk for or Infected with the AIDS Virus,* Chapter 6: *Issues for the Young Child in Foster Care,* and Chapter 9: *How to Do It Right: The School with HIV-Infected Students or Staff.*

Before proceeding in this book, you may want to look over the background material in Section 2, especially Chapter 10: *AIDS Information: Answers for Adults,* and Chapter 12: *AIDS Information and Developmental Stages: What Do Children Want to Know About AIDS, When?*

Chapter 4

What Are Children Asking, and How Can You Answer Them?

In this chapter we outline some suggested responses to the kinds of questions and comments children are presenting concerning AIDS and related issues. These answers are based on two important premises: *first,* that the adults in the child's life, including whoever is answering the question at hand, are not at significant risk for HIV infection; and *second,* that the child is neither at risk nor infected. For young children, it is important to offer this style of straightforward, confident and direct answer whenever possible. We know that many children *do* face more ambiguous circumstances, and we must also endeavor to be honest in our answers for them. We address approaches for these children in Chapter 5: *Special Circumstances: When a Child, Family or Friends Are at Risk for or Infected with the AIDS Virus;* and Chapter 6: *Issues for the Young Child in Foster Care.*

Remember the points we discussed in Chapter 2: *Things to Keep in Mind,* that will influence your responses to children's questions. They include your relationship with the child, the setting you are in at the time, your own reaction to the question, and what previous discussions you have had on related topics. The child's developmental level and "the meaning behind the question" will influence your answer as well.

Overall, you might think first about the child's level of sophistication concerning AIDS and related issues. This is not solely a function of age, but also of

maturity and previous learning. Some ten year olds may not understand the facts of human reproduction, while a five year old may be quite comfortable with and knowledgeable about this material. To suggest, "Here is a good answer for a five year old, while a ten year old will understand this other answer," will not work with many of these questions.

The responses we give in this chapter suggest only one of many possible good answers. These are the kind of answers a child could understand from a parent, teacher or other adult. Overall, we have tried to offer the simplest answers possible that address the question thoroughly. For example, rather than speaking of "the AIDS virus," we use the term "the AIDS germ." You may want to give answers that are a little more sophisticated, or build in some technical knowledge for a more mature child, but be sure he or she understands you.

We go into a fair amount of depth with some of these answers, *but it will not always be necessary to be so thorough in discussing AIDS-related concerns with children.* In many cases it would be appropriate to cover only the material in the first paragraph of the longer answers. For older or more mature children, or for a child who continues to have questions or seems dissatisfied with what is said, you can continue to explain the point. Generally, however, we believe you do best if you give the simplest answer possible.

Finally, we make one further recommendation, and that is always check in with a child after giving an answer to see what is understood and that you have responded to the meaning of the question the child asks. You can check by saying such things as, "Does that answer your question?" "I wonder if that answer makes sense to you." "Let's see if I explained that well—can you answer the question for *me* now?"

Suggested Steps in Answering Children's Questions

When a child approaches you with a question, following this sequence may be helpful.

1. Listen carefully to the question.
2. If the meaning behind the question is not clear, or to better understand the child's sophistication on the matter, reflect the question

back to the child with such comments as, "I wonder what you've heard about that," or, "Do you have any ideas about what the answer might be?"

3. Give a simple, concise answer.
4. Check back to see if the child understands your answer.
5. If the child continues to be interested in the matter, offer further information or otherwise continue the discussion.

Questions and Answers

What is AIDS?

AIDS is a very serious disease that some people get. Fortunately, it is also a very hard disease to get. You can't get it the easy way you get colds or flu. We're glad for that, because it means you and I don't have to worry about getting it!

For Older Children:

For younger children, this simple, clear and positive answer will be most useful. For older children, you may want to explain more about how AIDS is transmitted (see the next question), and reinforce that as long as the child does not engage in sexual intercourse or the sharing of needles in IV drug use, there is no reason to worry about contracting AIDS.

How do people get AIDS?

Like many diseases, AIDS is caused by a germ. Most people have gotten AIDS by having sex (sexual intercourse) with someone else who has the germ that causes AIDS, or by using drugs with needles and sharing needles with someone else who has that germ.

What is a germ?

A germ is a special kind of living thing that is so tiny you can't see it. It doesn't look like any of the animals or plants we can see—not like a bird or a dog or a flower. There are all different kinds of germs. Germs can live inside people's bodies. Most germs don't hurt people at all, but some germs make people sick. When you have a cold, it is caused by a kind of germ.

Sometimes we tell you to wash your hands, even when they look perfectly clean. That's because you might have germs on your hands that you can't see. Germs wash off with soap and water, and this helps you stay healthy.

For Older Children:

There are different kinds of germs, and we have different names for the different kinds. Most often, we hear about bacteria and viruses. There are other kinds too (fungi, protozoa). All of them are so small they can only be seen with a microscope.

What is Sex?

1. Answer given by teacher in a classroom setting with younger children:

Usually, when people talk about sex, they are talking about "sexual intercourse." When two grown-ups feel very close to one another, they may snuggle very close and kiss. They also may decide to have sexual intercourse. They will usually take their clothes off and the man will slip his penis into the woman's vagina. Sexual intercourse is something grown-ups may do, but it is not a good idea for children.

(Why isn't it good for children?)

Children's bodies have lots of growing to do. Your bodies are not ready for sexual intercourse. When your bodies are all grown up, it will be time for you to decide whether to have sexual intercourse or not.

2. Additional information for older children or where greater interest is expressed by younger children:

Sexual intercourse is also the way that babies are conceived. The man has sperm in his body. Sperm are so small, you cannot see them without a microscope. During sexual intercourse, these tiny sperm can travel out of the man's penis and into the woman's vagina. Then the sperm may move into the woman's uterus and meet an ovum (egg). If a sperm and an ovum join, a baby will start growing in the mother's uterus.

3. Answer given by a parent:

Sex is a way for grown-ups to feel good about themselves and close to someone else. Usually, when grown-ups have sex, they snuggle very close and kiss, and they might take their clothes off. There are lots of other ways people can feel good with sex. Sometimes, people have "sexual intercourse," which is when a man slips his penis into a woman's vagina.

Some children have sexual feelings, and you might too. Maybe you've touched yourself on your clitoris (or penis), and it felt good. That's a sexual feeling. People have sex in this private way of touching themselves, which is

called "masturbation."

Sexual intercourse or sex with someone else is something just for grown-ups to do. It is not for children.

Note:

Parents can add further information about reproduction or other sexual activities if children express continued interest. The answer to this question will be closely tied to parents' values, and our example may not be appropriate for some parents. Because this is such an important concept to discuss with children, and because parental values are so essential in this answer, we encourage parents to plan an answer that does feel comfortable and correct for them.

What are IV drugs?

"IV" stands for a big word: "intravenous." That is when someone puts medicine right into the veins that carry blood all through the body. Sometimes doctors will help sick people by giving them medicine this way. They use a needle to get the medicine into the vein. It's kind of like when you get a shot. Some people use other drugs like this on their own, without a doctor, because they like the way it makes them feel. But IV drugs are very dangerous without a doctor's help, so it would be better if people never did this. It is against the law for people to use IV drugs without a doctor's help.

What is "sharing needles"?

This is something that happens when people use IV drugs without a doctor's help. It means that one person uses a needle to take some drugs, and then another person uses that same needle.

What is oral sex?

We've talked about how grown-ups can be sexually close in many ways. Oral sex is one way of having sex, when one person puts his or her mouth on another person's penis or vulva.

What is anal sex?

You know where your anus is—it's the place your BM's come out of. Some people enjoy the sexual feelings they have when they touch their anus.

Sometimes a man might put his penis into his partner's anus. These are ways of having anal sex.

How do people pass AIDS while they have sex?

Remember that AIDS is caused by a very tiny germ that you can't see or feel. When people have sex (sexual intercourse), this tiny germ can move from one person's body to the other person's body. It's a little bit like drinking out of someone's cup if he or she has a cold—you might get the cold. ***Very important to include in your answer:*** The AIDS germ isn't passed on cups, but it can be passed from one person to another person during sex.

For Older Children:

Older children familiar with terms like "semen" and "vaginal secretion" might like to hear a fuller explanation of this process—that the germ (virus) can live in blood, semen or vaginal secretions; semen and vaginal secretions are exchanged during some kinds of sex; and that a person could also pass the AIDS virus in this way if he or she were infected. The idea that small quantities of blood are sometimes passed during sexual contact may disturb a young child and make sex sound very frightening. This detail will best wait for a later age.

What is semen?

Semen is a liquid that comes out of a man's penis sometimes when he has sex. It carries sperm, which can join with a woman's ovum (egg) to make a baby.

What is vaginal secretion?

A woman's vagina is a warm, moist place. It's a little bit like the inside of the mouth. "Vaginal secretion" is what we call the moisture or wetness inside the vagina.

Can my dog get AIDS? He has sex with lots of other dogs.

Dogs and cats do not get AIDS, so you don't need to worry about that. Usually, animals only get animal sicknesses and people only get people sicknesses.

How do people pass AIDS using IV drugs?

When people are using IV drugs without a doctor's help, they often share the

needles with other IV drug users. A little bit of blood is usually left on the needle after one person uses it. Someone who has the AIDS germ in his or her blood might use a needle and then let someone else use it. That next person might get the AIDS germ in his or her body.

Be sure to mention: You don't have to worry about this if you are seeing a doctor and have to get a shot. Doctors *always* use clean needles. A needle is used only once, on one person. Then the needle is thrown away. There is no way to get AIDS or any other disease from a clean needle.

Is it safe to be around (play with) someone with AIDS?

Yes, it's perfectly fine. You can talk to and hug someone with AIDS. You can eat together. You can watch TV together. You can do anything you would do with your other friends, and you won't catch AIDS.

When I have a cold, I am very careful not to give it to someone else. Why would someone who has the AIDS germ do anything that might give it to someone else?

Many people who have the AIDS germ don't know they have it. They can't see it or feel it, and it hasn't made them sick. They don't know that they might pass the germ to someone else.

While it's true that a few people who have the AIDS germ might be careless about other people, that's unusual. Almost everyone who knows he or she has it is very careful to protect others.

What does "gay" mean? (What does "homosexual" mean?)

A gay, or homosexual, person likes to be close to and sexual with someone of the same sex—men with men and women with women. A person who likes to be close to and sexual with someone of the other sex—women with men—is called heterosexual (or straight). Some people are bisexual, and this means they like to be close to and sexual with both men and women.

Why do gay men get AIDS?

Anyone can get AIDS if they have sex (sexual intercourse) or share needles with someone else who has the AIDS germ. Gay men were probably the first people in this country who got the AIDS germ. Since gay men had sex with other

gay men, the germ got passed on between them. Most of the people with AIDS in this country today are gay men.

In other countries, people with AIDS are mostly heterosexual men and women.

How can people be sure they don't get AIDS?

If a person doesn't have sex with anyone and doesn't use IV drugs, he or she doesn't need to worry about getting AIDS.

We can all live well without using IV drugs, but most grown-ups *do* want to have sex sometimes. We know ways to have sex that protect us from getting the AIDS germ.

One way is for people to use a condom for sexual intercourse. Condoms work pretty well to keep the AIDS germ from passing between people during sexual intercourse.

Another way is for someone to have sexual intercourse with only one other person. Many people who are married do this. If two people know they don't have the AIDS germ, they don't have to worry about passing it to each other.

What is a condom?

A condom is a thin piece of rubber that looks kind of like a balloon. It fits over a man's penis. When the man has sex with someone, the condom keeps his semen from getting into his partner's body. Some couples use condoms to prevent pregnancy. If semen can't get into a woman's body (uterus), she won't get pregnant. Condoms can also keep the AIDS germ from being passed from one person to another person.

Condoms get used once and then thrown away. Men don't wear them all the time—just if they want to while having sex.

What is hemophilia?

If you cut or scrape yourself, you might bleed a little bit. After a few minutes, the bleeding usually stops. That's because your body tells your blood to *clot*. That's what happens when your cut forms a scab and stops bleeding.

Hemophilia is a disease some people are born with. A person with hemophilia might not stop bleeding if he is cut or hurt because the disease keeps his blood from clotting.

Doctors help people with hemophilia by giving them special medicine. The medicine is made from other people's blood. (Remember that the AIDS germ can live in blood.) Some people with hemophilia got the AIDS germ in their body after taking this medicine. Now doctors know how to fix the medicine so the AIDS germ isn't in it any more.

Be sure to mention: The medicine for hemophilia is a special kind. The medicines you sometimes take do not have any AIDS germs in them—we are sure of that!

You can't catch hemophilia from coughs or cups, like people can get colds, or from sexual intercourse, like people can get AIDS. It is a disease people are born with, and if someone has it, the doctors find out about it right away. We know you don't have hemophilia because you are too old to get the disease now.

What is a blood transfusion?

A blood transfusion is when blood is taken from one person's body and put into someone else's body. **(Why would anyone want to do that?)** Sometimes if someone is hurt very badly, he or she might bleed a lot. If a person loses a lot of blood, he or she might need some more blood to get well. Other people who are healthy let doctors take a little bit of their blood. Then the doctors can put that blood into the person who needs it.

Remember, the AIDS germ can live in blood. There were times that a person with the AIDS germ donated, or gave, his or her blood to doctors to use for someone who was hurt. The person receiving the blood got the AIDS germ in his or her body.

Now doctors know how to check blood to make sure it is safe, and people who think they might have the AIDS germ no longer donate blood.

Does AIDS hurt?

Most people with AIDS feel sick a lot of the time. Some people with AIDS feel okay. AIDS hurts during the times people with AIDS feel sick.

Can doctors make people with AIDS better?

Sometimes doctors can help people with AIDS feel better, but no one knows how to get the germs out of the body once they have gotten in. This means most

people with AIDS might get better for awhile. They will usually feel sick again later.

How long are people sick with AIDS? My colds usually last a week.

This is one of the things that makes AIDS such a serious disease. People with AIDS will probably be sick their whole lives. AIDS doesn't go away the way a cold does.

How do you know if you have AIDS?

Most people with AIDS get very sick and have to go to see their doctor or go to the hospital. The doctor will examine them and may do some tests. The exam and the tests will usually tell the doctor that the person has AIDS.

Note:

Lists of symptoms should be avoided unless a child is asking about them directly. The symptoms for AIDS—fever, coughs, tiredness, trouble breathing, etc.—are so general, talking about them might add to the anxiety of a child who almost certainly experiences such symptoms on occasion, and sees others experiencing them as well.

Do people get AIDS from being bad? (Are people with AIDS being punished for doing bad things?)

No. People get AIDS because the AIDS germ got into their body somehow. Some people get AIDS from having sex with someone who has the AIDS germ. But sex isn't bad and neither are people who have sex.

Some people get AIDS from using drugs and sharing needles with someone who has the AIDS germ. The people who do this are not bad, but it *is* bad to use drugs this way.

Do bad people get AIDS?

All kinds of people get AIDS. Getting AIDS doesn't have anything to do with whether someone is good or bad.

AIDS is caused by a germ. Germs don't know whether a person is good or bad.

Note:

This question and the previous one may express a child's anxiety about his or her own "goodness" or "badness." Answers should be very reassuring.

How do children get AIDS?

If a woman who has the AIDS germ gets pregnant and has a baby, the baby might get the AIDS germ from her. This is how most children with AIDS have gotten it.

Some children who were very sick with some other illness were given special treatments by their doctors called "blood transfusions." This means that a little blood from a healthy person is given to a sick person who needs it. The AIDS germ was in some of the blood used for transfusions, so some children who received blood have gotten AIDS. Doctors know how to check the blood now, so this shouldn't happen any more.

Some children have a disease called hemophilia, and they need a special medicine made partly from blood. Some of this medicine had the AIDS germ in it. Some of these children got AIDS this way. Doctors know how to fix the medicine now so this shouldn't happen any more.

Be sure to mention: You can see that most children, including you, have never had these things happen, so they—and you—don't need to worry about getting AIDS.

What happens to children with AIDS?

Children with AIDS are a lot like other children with serious diseases. They are often quite sick. They see doctors who help take care of them. Sometimes they have to stay in a hospital for awhile. When they feel better, they can go home again.

Sometimes children with AIDS are so sick that the doctors can't make them better, and they may die.

Maybe you have heard about things that happen to children with AIDS. I wonder if you can tell me what you know.

Note:

This is usually a question stemming from a child's anxiety about the terrible things that can happen to children in general. Many children have heard news stories about ostracism, neglect or abandonment of children with AIDS and their families. Answers here should seek to lower anxiety and avoid frightening or explicit detail about such cases.

Why would a mom and dad give away their baby who has AIDS?

It is a very sad thing, but some moms and dads just aren't able to take good care of their children. Sometimes moms or dads are sick, and taking care of kids is too hard for them. When this happens, there might be someone else who can care for the children. It might be grandparents, or an aunt, or a person who does not know the family but likes to help out children like this.

I don't think that these moms and dads give away their babies because the children have AIDS. I think they just feel like they can't give their children the care they need. Then they try to find someone else who will be able to care well for the kids.

Be sure to mention: We (your parents) would never want stop taking care of you. We (they) like having children to care for very much!

Note:

This is another question that will usually be best answered by reassurances that the child asking the question has a secure place in his or her home.

I think I might get AIDS. (How do you know I won't get AIDS?)

1. Answer given by parents or caregivers:

First response: I wonder why you think you might get AIDS. *[Elicit response from child.]*

Second response: It's true that anyone *can* get AIDS, but we also know how AIDS is passed from one person to another.

Remember that people can get AIDS by sharing needles for IV drug use, or by having sexual intercourse. Are these things that you have done? *[Elicit response, which is hopefully "no."]* Are there other things that have happened that worry you? *[Elicit response, reassure.]*

Since you haven't done the kinds of things that pass AIDS, I know you don't have and can't get it.

Note:

This question usually reflects a child's anxiety, and is best handled by appropriate reassurances of the child's safety. In some cases, a child may be making reference to incidents of sexual molestation. In other instances, a child may be worried about receiving shots during a doctor's visit. Explore the child's concerns carefully and respond accordingly.

2. Answer given by a teacher in a classroom setting:

There are only a few ways people can get AIDS. Remember that people can get AIDS if they share needles while using drugs, or if they have sexual intercourse with someone else who has the AIDS germ. Most children have never done these kinds of things. I don't think you will need to worry very much about getting AIDS right now.

If any of you *do* have more questions about something you have done, or something your friends have done, you can talk with me privately.

Note:

Once again, the overall goal is reassurance. Teachers will not want to elicit personal data from students in a classroom setting. If references are made to specific anxieties, speak with children privately if necessary to help them understand and resolve their concerns. And, again, be familiar with appropriate responses in cases of suspected sexual abuse should the need arise.

Can I get AIDS from getting a shot at the doctor's?

No, you don't need to worry about that at all. The needles doctors and nurses use are very clean. They have never been used on anyone before. After you get your shot, the needle is thrown away. It won't be used on anyone else. This way, we know that no diseases will be passed from one person to another person because of these needles—not AIDS or anything else.

Do moms (dads) get AIDS?

Some people with AIDS are mothers. Your own mom knows about AIDS and she knows how to make sure she doesn't get it, so you don't need to worry about her.

Still worried? [Yes.] Why don't we get together with your mom and talk with her about this.

Note:

Be sure to follow through on this suggestion as soon as possible. The general goal is reassurance. Children may be especially concerned if their parents have recently divorced, particularly if a parent has become sexually involved with a new partner.

Will you get AIDS? (asked directly of a parent.)

I know how to keep myself from getting AIDS, and I want you to know that I'm going to take good care of myself. You don't need to worry about my getting AIDS.

How long do people with AIDS live? (Does everybody with AIDS die?)

One of the reasons AIDS is such a serious disease is that people do die from it. It's a little different for everyone who has AIDS. Some people with AIDS live only a few weeks or months. Some have had the disease many years and are still okay.

This means we don't know how long someone with AIDS might live. We certainly hope that doctors can find medicines to help people with AIDS live longer and healthier lives.

For Older Children:

A more frank discussion with a mature child seven years or older might be appropriate, but usually the grim details of AIDS mortality are not helpful for young children.

Why does God let people get AIDS? Why doesn't he show doctors how to cure people with AIDS?

There are many things we don't understand in this world, and this is one of them. It is very hard to see people suffer. I think we can make our own lives better by doing all we can to help people who are suffering, and by trying not to make anyone unhappy.

How can people have babies now? If they have sex, they will get AIDS and die.

Some people have gotten AIDS by having sex with a partner who has the AIDS germ. But if two people want to have a baby and neither of them has the AIDS germ, they can't get AIDS from one another.

Most people in the world *don't* have the AIDS germ, so lots of people can have babies safely.

Will everyone in the world get AIDS and die?

No. Most people do not have the AIDS germ. As long as people know how to keep themselves from getting AIDS (don't use IV drugs, and don't have sexual intercourse with someone who has the AIDS germ), they won't get it. I'm going to be sure I don't get AIDS. What about you? See, most people will never get AIDS.

What happens when you die?

First response: What do you think happens? *[Elicit response from child.]*

Second response: When a person dies, the things that made him or her alive stop happening. He or she doesn't breathe any more, and blood stops flowing in his or her body. He or she doesn't talk or laugh or cry or move. His or her life is over.

We don't know exactly what happens then. People have different ideas about this.

Note:

In public classroom settings, teachers will want to avoid speaking personally about spiritual beliefs. In religious schools or personal talks with children, it may be appropriate to explore these ideas in greater depth. Certainly, parents can speak forthrightly with their children about their personal spiritual beliefs. Be honest with children about such matters. Don't make up things for children that you don't believe yourself. Don't tell children that dying is "like going to sleep, except you never wake up." This may lead them to greater anxieties about death and serious trouble with sleep.

This is an example of the way one parent we know described death to her seven year old:

"I believe when someone dies, the person's soul—an invisible part of him or her that feels feelings and cares for people—goes to a special place. Some people call this heaven. In heaven, all the things that hurt someone during life no longer hurt. I think it's a nice place to be."

What does a person with AIDS look like when he or she dies?

Most people who die of AIDS look like they have been sick for a long time. They will look the way people with other serious diseases look. They are often

very thin because it has been hard for them to eat. Often, people also look calm and peaceful when they die.

I don't want to eat dinner at this table. Does anybody here have AIDS?

Let's remember some of the things we've talked about concerning AIDS. You remember how people can get AIDS—they share needles in IV drug use or have sexual intercourse with someone else who has the AIDS germ.

We're certainly not going to use IV drugs or have sexual intercourse at this table! None of us need to worry about getting AIDS here.

Note:

Many children will bring up comments like this about AIDS. They may be genuinely concerned about their risks, and if this is your sense of the situation, a careful explanation is called for. Often, however, this is more an attention-getting device or a general expression of anxiety about AIDS. Careful explanations that don't make a big deal out of things are still probably the most useful response. If comments involve harassment—"AIDS cooties! AIDS cooties!"—we think firm intervention and limit setting is called for. Children should not be encouraged to use AIDS concerns as a way to harass others. We give a further example of this sort of circumstance in Chapter 8: Trouble Shooting: Anticipating Problems that Might Arise in Discussing AIDS with Young Children.

Chapter 5

Special Circumstances: When a Child, Family or Friends Are at Risk for or Infected with the AIDS Virus

The sample answers given in Chapter 4 were based on the premise that neither the child asking questions, the child's parents, nor other important adults around him or her were at significant risk for AIDS. Sadly, there are children who have parents, family or friends at risk, and there are children themselves who are at risk. In these instances, a different approach is called for.

In high incidence areas for AIDS, a surprising number of children know someone with AIDS or ARC. One San Francisco teacher reported that one-third of his elementary students were acquainted with someone who had been diagnosed with AIDS. A teacher from a New York neighborhood with a high population of IV drug users told us that in his school, there were children in almost every class who had lost a parent to this disease. In other locales, the numbers may be less striking, but there will be many children throughout the nation who are similarly touched by the AIDS epidemic. It is important to keep this possibility in mind when we answer children's questions about AIDS.

We believe that there are two basic guidelines to keep in mind when talking with young children facing such situations:

1. We should never lie or be dishonest in our answers.
2. We should monitor our answers and be selective in what we say, so that we do not unnecessarily burden a child with circumstances over

which he or she has no control and for which the child may feel responsible.

It is also helpful to keep in mind that concepts of past, present and future are difficult for young children, and the distinctions between long and short periods of time are not always clear. As adults, when we hear that someone has tested positive for the HIV antibody or has been diagnosed with ARC, we worry that the person's lifespan may be shortened. We start to think of remaining life in terms of years instead of decades, and this possible shortening of time may sadden or frighten us. If a friend is actually diagnosed with AIDS, we remember phrases we have heard like, "the average person with AIDS lives less than two years after the time of diagnosis." Our friend may live only one or two more years. How tragic and terrible this anticipation seems!

But to a young child, two years is a very long time. A seven year old probably does not remember much in his or her life before the previous two years—this is almost like a whole lifetime. These different concepts of time become important when you talk to children about AIDS. If you say to a child, "Our friend has a serious disease, and he might die soon," the child may well expect the death to occur within moments or hours when what you have in mind is months or years.

We are also challenged by questions like, "Will my mom get AIDS?" when the child's mother is known to be HIV-infected or to have a risk. Reassurance, one of the major goals in all of our answers so far, is more difficult to offer here. Equally difficult is talking with a child known to be infected who asks, "Will I get AIDS? Will it hurt? Will I die?"

In one sense, a diagnosis of AIDS or ARC in a family member is not much different from having any other life-threatening disease. The sick person usually needs special care at times; there are visits to doctors and hospitals; nurses and other care providers may visit the house; many sad people are about; finances can become difficult; the house may smell funny; children sense greater tension among adults in the home and are scolded for making noise or asking for attention. The children may feel neglected or abandoned or jealous of the attentions the ill person receives. Routines are disrupted. In general, it is a challenging time for a family.

In some other important ways, however, AIDS is a different sort of illness. Most significantly there is the issue of stigma. People are often ostracized if they are known or suspected to have AIDS—some families have actually been evicted from their homes when it is learned that a member has AIDS. Children on playgrounds make jokes and tease one another about AIDS. "AIDS tag" is a popular game in some places (when you're "it," you have AIDS and try to pass it on to other players by touching them). There is still much fear of casual contagion among people generally. Another concern is the special quality of hopelessness often associated with the disease. To date, there are no successful treatments and we commonly hear that AIDS is a "universally fatal disease." We are acquainted with individuals doing fairly well after six years with a diagnosis, and others who are known to have been HIV infected and asymptomatic for ten years, but such hopeful stories are rarely told. Finally, in the many families affected by AIDS who also face problems of intravenous drug use, there are other difficulties present and few resources available for the needs of children or sick people.

Generally, when children are close to someone who is HIV-infected, we recommend they be given a message of concern and hope. "Yes, Helen has AIDS and we are very worried about her. But she is doing okay right now and we hope her doctors will be able to keep her feeling well and strong." A young child does not need to spend two years anticipating the death of a friend.

When a parent is ill, the child's anxiety and concern will be much greater, but our message can continue in the same vein. "Yes, Daddy is sick with ARC. He is doing all he can to keep himself strong and healthy and he has good doctors who are helping him too. Right now, things seem to be okay."

If the disease progresses and the person is obviously becoming more ill, it is appropriate to discuss this openly with the child. "Remember last Halloween, when Helen went trick-or-treating with us? She was strong then. Now it is Christmas and she doesn't seem to have much energy, does she? We are still hoping she will feel better soon, but she may not. What do you think about that?"

When a child is close to someone dealing with any life- threatening illness, it may be helpful to discuss ideas about death and dying in general, outside the context of the sick individual. This will help you establish an understanding that will be of use later if the individual does enter a terminal phase or die. The possibility of the person's death should also be discussed frankly with the child,

but one must think carefully about when it will be most helpful for the child to talk about these things. Certainly if the child asks specific questions about a person's possible death, they should be answered honestly and sincerely. It is difficult to make many other generalizations about the right time to bring up the topic, but in the broadest sense our guideline is to do so at the point at which further decline seems likely and death is expected within a matter of weeks.

Often the question arises, "Should we tell our young child that her father (uncle, cousin) has AIDS or ARC? Should we actually use those words? Or can we just say that he has a very serious illness?" Often, it is not especially important that young children know what specific disease is causing their father's illness. With AIDS, however, we think it is best that the words *are* spoken to the child. In most families dealing with a member who is quite ill with AIDS or ARC, these terms will be spoken in other settings—during telephone conversations with friends, during visits from nurses or family, and so forth. Therefore, it will be much better for the child to learn directly from a parent or other close family member just what is going on, rather than to overhear it in some conversation they are not supposed to be a part of. There is no question that when most children five or older hear the word "AIDS," they have some image of the disease and its meaning. Clear and open communication can help correct misunderstandings and build the sort of trust that will greatly benefit the family as the disease progresses.

When a young child is HIV-infected, we continue to believe that long anticipations of pain, disability or death are not at all helpful. If a child is asymptomatic, there is no reason to prepare him or her for times when he or she might become ill. This will only create anxiety and agitation.

Exactly what a family says to an infected child depends a great deal on that child and the particular family circumstances. This will vary for each family. We encourage parents of children who are HIV-infected to talk this over with their primary care physician and to seek support from a social worker or therapist familiar with issues of children with HIV infection or other chronic, life-threatening illnesses. Most hemophilia treatment programs have trained staff capable of helping families with hemophilic children in this situation.

We share below some case experiences that we hope shed light on some possible approaches in talking with children in these difficult situations. For

more in-depth explorations of children's attitudes towards life-threatening illness, please see the *Further Resources* section.

Tinisha: Having a Mother with ARC

Tinisha was an eight year old who was referred to a pediatric clinic by her mother's physician. The physician told the clinic that the mother was an IV drug user currently enrolled in a methadone program and was concerned about her daughter's health. Tinisha had presented a variety of complaints, including headaches, sore throats, abdominal pain, and leg pains. She appeared at her clinic appointment accompanied by her mother, Renee.

Tinisha was a bright, energetic and confident girl, extremely social and talkative. She interacted excitedly with the clinic staff and had an insatiable curiosity about all of the equipment around her. "What is that for?" she would ask. "Can you show me how you use it?" She smiled delightedly when someone took the time to explain things to her. In a busy clinic seeing many children each day, she was a special child, remembered by all who came in contact with her.

On physical examination, she appeared robust, alert and healthy. She did not complain of any pains and was vague and unclear when asked about them.

The clinic doctor spoke with Renee in private after the exam. She explained that there appeared to be nothing wrong with the child. Renee replied, "I have had ARC for the past year. Tinisha doesn't know this. I know, however, that I may have been infected with HIV long ago and I am concerned that her symptoms now mean she may also have ARC—perhaps she was infected by me before she was born."

The doctor reassured her that Tinisha's physical symptoms, her age and her general health all suggested that this was highly unlikely. The possibility of running an HIV antibody test was discussed—this could certainly verify the doctor's sense that Tinisha was healthy. Renee was uncertain about the test, however, and felt unable to make an immediate decision about whether she should request this. The doctor suggested she come back with Tinisha in a couple of weeks, and think about whether she felt the test was necessary.

The doctor asked Renee if she planned to discuss her ARC diagnosis with Tinisha. Renee said she felt well and did not want to burden her daughter with

this information. The doctor looked forward to seeing this family further, to try to get a better sense of what sort of support might be most helpful for both mother and child.

At their appointment two weeks later, Tinisha was a transformed child. She was quiet and subdued, keeping her eyes focused on the ground. Renee was also distraught. The doctor asked how they were. "Tinisha overheard her cousin talking on the phone a few days ago, telling someone that I had AIDS," Renee answered.

The doctor was silent for a moment. Then she turned to Tinisha. "What did you hear your cousin say?"

"She said my mama was a junkie, and that she had AIDS," she answered quietly.

"What is AIDS, Tinisha?" the doctor asked softly.

"AIDS is a disease," she said, slowly and deliberately. "The doctor can't do anything about it. There are no medicines. If you get it, you die."

"And do you think your mother has AIDS?"

"I *know* she has AIDS. The kids at school saw her on TV."

"Saw her on TV?"

Renee explained, "I was on a local TV show, trying to get people to make donations to a food program for people with AIDS. I guess some of her classmates saw the show."

"Yeah. And now no one will play with me. They all say that I have AIDS. I don't have any friends. I'm not going back to school."

Renee looked shocked. "Tinisha. You didn't tell me that. I don't understand—you and I talk about everything. Why haven't you told me about this?"

"I didn't want to make you sad," Tinisha told her, starting to cry.

"Oh, sweetheart," Renee said, and her eyes filled with tears too.

"It sounds to me," the doctor said, "like the two of you need to talk about this."

Renee agreed. "But I don't know what to say to her now. I don't know where to start."

"Maybe we could do a little of the talking right now," the doctor suggested gently. "Tinisha, do you want to ask your mother any questions?"

"Yes," said Tinisha, looking directly at her mother. "Do you have AIDS?"

Renee looked nervously at the doctor, who nodded for her to answer. "Well, Tinisha, I have an illness that's sort of like AIDS. It's called ARC. Sometimes ARC isn't quite as serious as AIDS."

"Are you going to die?" Tinisha asked.

"I don't know. I hope not. You know I see the doctor now, and I'm hoping he will help me stay healthy." There was a moment of silence. "I want you to know I'm doing everything I can to stay healthy and strong."

Tinisha nodded, looking serious. "I will try to help you stay strong," she said.

"Tinisha," the doctor said, "I think one of the ways you can help your mother is by asking her questions when you have them, and by telling her about the things that happen to you at school. She wants to know about these things."

"Yes, I do," Renee agreed.

"I wonder if you'd like the name of a counselor who would be able to meet with the two of you, to help you talk about these kinds of things, or other things that might come up."

"I'm not crazy!" Tinisha said. "I don't want to see a counselor."

"No, Tinisha, I don't think you're crazy. This counselor is someone who helps people when they have sad hearts. Sometimes he can help them fix their hearts so they feel better."

Tinisha was silent.

"Would you give it a try?"

"I guess," she answered slowly.

"We both will," said Renee. "We'll both give this a try." She reached over and hugged Tinisha.

The doctor examined Tinisha, and again discovered no physical problems. In private conference with Renee, they discussed the antibody test further. Renee decided against having Tinisha tested, but she did accept a referral to a psychologist. They were invited to return if there were any further physical complaints.

Renee checked back with the doctor a few weeks after starting regular sessions with the psychologist. She felt the meetings were helping both of them, and reported that Tinisha's physical complaints seemed to be subsiding and that she was doing better with her peers at school. Renee's health remained stable and she was satisfied with how things were going.

On a longer term follow up, six months after the first visit to the clinic, Renee's health was failing. She had been diagnosed with AIDS after developing pneumocystis pneumonia the previous month. Tinisha continued to attend school and see the psychologist regularly, and she was socializing well with her peers. Tinisha's future is uncertain—a grandmother living out of state is not interested in taking custody of her, and there are no other family members. It is not clear who will care for Tinisha when her mother is no longer able to do so.

***Comment**: Tinisha's presenting symptoms were probably a psychological response to her mother's illness. Basically, they "worked"—because of Tinisha's complaints, Renee was able to ask for help for the family. The physician played an important role in perceiving what the real problem was: Tinisha needed Renee to talk to her about her illness. The doctor helped the family start addressing the issue, and made an appropriate referral where they could get further support. Both the family relationships and Tinisha's symptoms improved dramatically once these supports were in place.*

It was particularly important that this work be done with this family, and done quickly. Tinisha was able to re-establish a confident and loving relationship with her mother before the illness worsened. There were fewer "secrets" about her mother's illness, and Tinisha understood that Renee was doing everything possible to stay alive and continue to care for her. It is likely that the child's future will be difficult—she is an older child, daughter of an IV drug user, daughter of a person with AIDS. The care she receives after her mother's death will probably be through the foster system, and the harsh reality is that she may be placed in a setting unable to address her needs well. This legacy of love and understanding with her mother will be essential to her chances of future well-being.

Lucas' Family: A Boy with AIDS

Lucas was a five-year-old boy who was diagnosed with AIDS. He contracted the disease through a blood transfusion. He had two older brothers, ages seven and ten, and a two-year-old sister. His parents asked to meet with a counselor who had worked with the family before. They were looking for guidance and reassurance—were they saying the right things about Lucas' illness to their children?

His mother, Marilyn, explained: "All our kids have always been active and energetic. Lucas has been fairly sick now for several months, and there is quite a difference between him and his sister and brothers. They're running everywhere—all through the house—and he pretty much stays in bed or lies on the sofa in the living room. And now that his brothers will be out of school for the summer, I think we'll have a lot more activity around."

Steve, his father, said, "I know there is no easy formula here, but we're wondering if we're on the right track in what we say to the kids, and how to answer Lucas' own questions about his health."

"What sorts of things has Lucas brought up?" the counselor asked.

"The hardest," said his mother, "was this crazy day at home, all the kids were there, Steve was out working in the yard, the boys were running up and down the hall, Sharon, our girl, was in her crib crying, and I was taking a glass of water to Lucas. He looked at me and said,'Thank you. Mom, am I going to die?'"

"What did you do?"

"I started crying. I wasn't sure if it was all right for him to see me crying, but I didn't have much choice about it. I told him I didn't know what would happen, that we all die sometime, but I didn't know when that would be for anyone. Then he said, 'But I'm sick, and I'm going to die before all of you.'"

"That must have been very hard for you."

"Yes, it was. But I kept remembering everyone saying to be honest with him, not to lie to him. And there I was crying with all this chaos around me, and I said, 'Yes, Lucas, I think you probably will die before all of us.' Then he said, 'I don't feel very good right now. I wonder if I will feel so bad when I die.' This was very difficult for me. But I told him that I thought when he died it would be easier, and that we would be with him and do everything we could so he wouldn't hurt much."

"How did he respond to that?" asked the counselor.

"He just got sleepy and said he would take a nap. Later he seemed more rested and his mood was okay. He seemed fine."

"It sounds to me like you answered him very well. I think your guideline about being honest really worked with Lucas, and by helping to reassure him you allowed him to relax and focus on other things going on in his life besides his fear of dying."

Steve nodded. "I wonder about the other kids too. I wonder if they will be afraid of dying, seeing Lucas go through this. He loves to see them, and they like visiting with him too. But he's failing now...he's getting weaker and smaller and paler. It frightens *me*. What can it be like for his brothers and sister?"

"What do they say about it?"

"Well, not much. That's just it. They don't talk about him dying; they don't talk about how horrible he looks. Maybe they don't notice. I'm wondering if I should talk with them, at least with his brothers who are older."

"I'm sure they notice he's sick," the counselor responded, "but his appearance may not have the same meaning for them as it does for you, and his dying is probably pretty vague for them right now. What about the idea of bringing up the topic with them, having a special talk about it?"

"We did that when he was first diagnosed, which was almost a year ago. It was pretty emotional for all of us, especially Marilyn and me. You think it's a good idea to try it again?"

"Yes, actually I do. But I think what you might do is go some place special with the boys, give them some attention on their own—maybe a hike somewhere, a place where you can all be together without a lot of other people distracting you. Then you can bring up Lucas' illness and ask them how they're feeling about it."

"They might not have much to say."

"That would be okay. You could talk with them about some of your feelings, and it might help them to hear you."

"I do keep wanting to tell them that I'm sorry we don't have more time together. It's so hard, with work, and then four young kids and one of them so sick. It seems like we are either working, or cooking, or cleaning, or going to the doctor's."

"Yes, I think they do need to know that. And to know you are making an effort to be with them. That will be important to them."

"I have one more question," Marilyn said. "We have a sense of our need to talk about all of this with the older boys. I am not sure if there is anything we can do or say to Sharon. She's only two. She's obviously too young to understand much that's happening, but I worry that we're setting up some terrible trauma for her by ignoring her feelings about Lucas."

"What do you think her feelings about Lucas are?"

"Oh, mostly she adores him. She loves to visit him and she likes the attention she gets from him. Sometimes when he gets tired and has to stop playing with her, she gets very angry and screams. She sees him every day, and sometimes they even nap together."

"You make sure she gets to see plenty of him."

"Yes, as much as we can."

"I'm curious about why you feel like you're ignoring her feelings about Lucas."

"Well, we're trying to prepare the boys in some way for his decline. He's much weaker now than before, and I guess it seems likely he could die fairly soon. We have mentioned this possibility with them, although briefly. But I don't know any way to prepare Sharon for this loss. Is that just what happens when you're two? You love someone and then that person is gone and you get over it? It doesn't seem fair."

"No, it isn't fair. But what isn't fair about it is not so much that she can't be prepared for it, but that she will lose Lucas at all, don't you think?"

"Yes, I guess so."

"Sharon is much too young to anticipate the future or to understand Lucas' death the way we will. She will understand it, when it happens, in her own way. You can talk to your boys about Lucas. With Sharon, your 'talking' will be different, and it will consist of letting her continue to love and enjoy Lucas as long as she can, and reassuring her of your love and presence after he dies."

"I suppose I knew that, but it helps to hear it said."

The counselor told Marilyn and Steve that they were handling the difficulties of Lucas' illness well, and that their caring and concern for him and the other children were certainly coming through in their communications with them. This couple had a close relationship with one another and a commitment to their family that continued to help them through the course of their son's illness. Lucas died, at home and with all his family present, six weeks later.

Comment: *Marilyn and Steve's family had many strengths. They had an excellent understanding of Lucas' condition and good ideas about how to discuss the circumstance with their children. The counselor offered some important reinforcement for them as they worked out some of these issues.*

It might have been helpful if the counselor had explored what sort of support Marilyn and Steve had for themselves. They have a close marriage and certainly talk with one another. They might also benefit from the opportunity to discuss their feelings and concerns with people outside the family. Since they seemed to find the talk with the counselor useful, such support (with a pastor, more sessions with the counselor, or seeing close friends) would probably be helpful at this time in their lives.

The other children in the family might be assisted by therapeutic support, in group, individual or family settings. In some areas, there are support groups available for children who have a family member with life-threatening illness. For Lucas' siblings, especially his older brothers, there may be a need for some sort of therapy after Lucas' death as well. If the resources exist to offer such services, we think they are well worth exploring.

Jackie: A Father at Risk

Jackie is a six-year-old first grader. His parents are divorced. They live in the same community and share custody of their son. Hank, his father, and Maria, his mother, have a friendly relationship, and both are actively involved in Jackie's school activities. Jackie's teacher, Lucy, had met with Hank and Maria early in the school year, and during that meeting they had explained to Lucy that Hank was gay and that Jackie knew about this. They felt very strongly that any anti-gay sentiments that might come up among Jackie's peers would need to be addressed firmly by the school, and they wanted reassurances that their child would not be harassed in any way. Lucy informed them that a number of children in the school did have gay parents, and that the teachers and administrators were clear about teaching the students to welcome the many diversities in their school community and not to discriminate towards other students or their families.

Lucy was reminded of this meeting with Jackie's parents when she was on schoolyard duty one morning and heard a group of children teasing one another, "You're a fag. You're a fag. You've got AIDS!" She quickly intervened and informed the students that their behavior was unacceptable, but she noticed

Jackie standing not far away watching the scene. She started to approach him after she had finished speaking with the other boys, but the recess bell rang and he ran off to his class line.

After this incident, Lucy began to notice that comments about AIDS were fairly common on the playground, and occasionally she heard remarks made in her classroom as well. She kept her eye on Jackie, and wondered if the AIDS jokes were having an effect on him—did he make any connection between his father's being gay and this topic of play and ridicule? One day she saw him with a friend during recess. The two of them were taking turns lying down on the ground and covering their heads with a jacket. She walked over to them.

"What are the two of you doing?" she asked.

"We're playing AIDS," Jackie answered.

"How do you do that?"

His friend answered, "You lie down on the ground and get sick and die. And then you get covered up with a sheet."

"How do you like it?" Lucy asked.

"We like it a lot," they both answered, and began poking and teasing each other, laughing and falling on the ground. Lucy walked on, uncertain how to respond to the boys' game. Were Jackie and his friend working through normal childhood anxieties about death, responding to the current concerns about AIDS being expressed by other students on the playground, or were they acting out some damaging drama that should be altered or stopped? Was it healthy or unhealthy? What, if anything, should she do?

In a faculty meeting the next week, Lucy brought up her concerns about AIDS "play" in the schoolyard and its potential effect on students with gay parents. Some of the teachers shared her feelings, but others believed strongly this was not of any consequence. One of the teachers suggested that they plan a school-wide educational effort about AIDS, to help clarify the students' misconceptions. The principal made it clear that schoolyard play that ridiculed or denigrated any groups—gay, ethnic, religious or anything else—was not to be tolerated, and that playground monitors should act accordingly if such activity was going on.

The meeting concluded after assigning a task force to explore approaches to classroom programs on AIDS for young children. Despite the protests from some teachers, it seemed possible that before the school year ended, the

teachers would be given some guidelines for classroom discussions about AIDS. Lucy was encouraged by this, but felt that something more personal and immediate was called for in Jackie's case.

The next day, she invited Jackie to help her rearrange one of the bulletin boards in class during the lunchtime recess. She often had students come in to help her with these kinds of tasks, so her request was not unusual. Jackie excitedly agreed to come back to the class as soon as he had finished his lunch. When he arrived, he was energetic and eager to work. They pulled papers, string and cutouts down from the wall, and chose new pictures to put up. As they worked, they talked, and Lucy guided the conversation carefully.

"How are your parents doing?" she asked.

"Oh, they're fine," Jackie answered. He told her about a recent trip they had taken to the beach, where they had built an open fire and cooked hot dogs.

"Do you spend more time at your mom's house, or at your dad's?" she asked next.

"It's about the same, I guess. I spend maybe a little more at my mom's, because I have more chores to do there."

"What sorts of things do you do with your dad?"

"We go for walks. We go to movies. He has a walkie talkie at his house. Last week we went to the laundromat, and I got to put all the quarters in. It was neat."

Lucy was feeling lost. All of her carefully orchestrated questions were not helping her find out anything about Jackie's thoughts about AIDS.

"Jackie, I wonder if you ever worry that your father is sick?" she asked.

He looked startled. "Is my dad sick?"

"Oh, no," she stammered. "No, I don't think so. I just thought you might worry that he is."

"My dad is fine. He runs five miles. He is very strong."

"Yes, I know he is." She paused a moment. "Jackie...I hear a lot of kids in the school making comments about AIDS and gay people. And I know your father is gay. I just wonder if these comments bother you, or if you have any questions."

Jackie's eyes filled with tears. "I don't know why they say those things. They say that all the faggots are going to die. They say they will all get AIDS and die." He began to sob, and Lucy put her arms around him until he had calmed down a little. "Is my dad going to die?" he asked her.

"It sounds to me like you dad is just fine," she replied. "But I wonder if you have talked to him about this?"

"He hates it if the kids make comments about gay people. He gets mad. I don't want to tell him."

"You like to talk to your dad about other things?"

"Yes."

"How would it be if I give your dad a call and tell him you would like to talk to him about this? I can ask him if that will be okay. Then you can talk to him if you want."

"Do you think that would be okay?"

"Yes, I do. How does that sound?"

Jackie nodded and said, "But I have to get out to the playground now. I'll see you later."

Lucy made the call to Hank that evening and told him about her discussion with Jackie. He was interested to hear it and said he would certainly talk further with Jackie. He wanted to do so soon, and thought he would bring it up the coming weekend.

Jackie continued to be an active and charming boy. Lucy did not notice any changes in his responses to AIDS talk on the playground or his participation in AIDS "games," though she did believe his father had followed through with his plans to have the discussion with Jackie. This was the first time she had dealt with a situation quite like this, and in retrospect she felt she might have done better by calling Hank first rather than arranging the lunchtime meeting with Jackie. She also realized that she did not have any idea whether Hank was HIV-infected, though many gay men in her city were. She continued to advocate for AIDS education programs for the school. She also felt that the whole experience had sensitized her to the presence in the school of children like Jackie, whose parents might or might not be HIV-infected, and to have special consideration for the uncertainty these children might be living with either currently or at some future time.

***Comment**: Lucy's sensitivity to Jackie was important in this circumstance. We agree with her that a direct call to the parent might have been a better way to proceed. In fact, since she already knew that Hank and Maria were involved and supportive parents, she probably could have set up a meeting with the two*

of them to discuss the issue—Maria's relationship with Jackie will also be affected by his concerns about his father, and she would benefit by knowing about these events. At such a meeting, Lucy could set up further follow-up with both parents by telephone, to see whether they had spoken with Jackie. This would help her maintain her sensitivity to him.

Lucy has also shown us how powerful sincerity and caring can be for a child in Jackie's situation. We saw the difficulty this circumstance presented for her and the awkwardness she experienced in bringing up the topic. By persevering with Jackie, she was able to discover his genuine and serious concern, and help him take the steps necessary to resolve some of his worries.

Chapter 6

Issues for the Young Child in Foster Care

An IV-drug-using parent is especially challenged in his or her ability to care for children, and while most IV-drug-using mothers are very committed to their children, they are often unable to care appropriately for them. Many children whose parents are substance abusers become involved in the foster care system. In some communities, the child of a mother who is a known addict will automatically be put in foster placement.

This means that a considerable number of urban foster children have an IV-drug-using parent. Because of this possibility, we think special care may be needed when discussing AIDS with foster children. They may be confused about the different risks of drugs administered intravenously and those taken by other methods. Children a little older may know if their mother is a prostitute, and may have heard that there is some connection between prostitution and AIDS.

Children in the foster care system may be accomplished "keepers of secrets." They understand that if they suggest such activities as drug use, prostitution, or sexual molestation are taking place in the home, they risk delaying their return to their family. Foster care providers may be unaware that risk activities are being practiced, and the children themselves may be unwilling to disclose these activities as the source of their anxieties about AIDS.

To further complicate matters, foster children are often living in ambiguous

circumstances, without consistent or reliable relationships with adults. They may be moved through several placements in a short period of time. Anxieties about their parents' risks for AIDS can only compound this already difficult situation.

Keeping these issues in mind, the foster parent or social service worker can speak sensitively to the child when AIDS comes up as a topic. Unless one is quite certain that a foster child's parents do *not* have a background risk for HIV infection, we think it is best to follow the guidelines outlined in Chapter 5: *Special Circumstances: When a Child, Family or Friends Are at Risk for or Infected with the AIDS Virus.*

As much as possible, the foster child should be provided with a confident and predictable environment. When there is anxiety, we hope to offer reassurance and safety. If a child asks questions about a parent's risk for AIDS, we wish we could reply with a confident and positive answer. These children have often been lied to, however, and honesty on our part is absolutely essential. If the child asks, "Will my mother get AIDS?" explore these concerns: "I wonder why you think that she might." If a risk seems likely or possible for the parent, speak honestly to the child: "I don't know whether your mother will get AIDS. She sounds okay right now, and we will hope she stays that way."

If it is possible to gather some information about the parents that could confirm or deny the child's anxieties, this might clarify how to respond to such questions in the future. In many areas, however, background information on birth parents is not made available to the foster parent. Whenever we are able to honestly assuage a foster child's anxiety in this regard, we do think this is well worthwhile.

Some interesting dilemmas may arise for the health care provider working with foster care children. In particular, we find that some foster children are having HIV antibody tests. Such tests may be administered through the wishes of the birth parents, by court order, or sometimes at the request of the foster parent. Many of these children are old enough to need information about what procedure is being done and why (usually by age three children will want some explanation of blood tests). *We do not think it is helpful to tell young children they are having their blood tested for the AIDS antibody.* This is likely to raise far more anxiety than necessary. A common and appropriate explanation is, "We are going to draw a little bit of blood and then run a test on it just to make

sure that everything looks okay and that your blood is healthy." We hope foster parents and other providers will keep in mind this particular possibility of AIDS-related anxiety for the children in their care. When such concerns are handled sensitively and appropriately, the already difficult burdens of the foster child will be eased a little bit.

Chapter 7

AIDS Education in the Early Elementary Classroom

Kathleen Middleton, MS, Editor for Classroom Materials at ETR Associates, contributed substantially to the concepts and content of this chapter.

Often the question arises, "If you think elementary school teachers should be addressing AIDS with their students, what do you believe they should be saying, and in what context? How should this material be handled in classroom settings?" Our purpose in this chapter is to demonstrate some effective ways of providing relevant and appropriate AIDS education to young students.

With students in kindergarten through fourth grade, specific units on AIDS will usually not be necessary. The exception to this might be in schools where there are known HIV-infected students or staff present. This circumstance is addressed in some detail in Chapter 9: *How to Do It Right: The School with HIV-Infected Students or Staff.* For the children we are considering here, we believe the essential task of the school is to provide carefully planned, comprehensive health education. Such education will lay the groundwork for later understanding of AIDS and AIDS prevention. It will provide teachers with tools to explain AIDS as necessary, should students raise questions about the disease during other classroom lessons.

Young children need help and practice to develop the kinds of concepts and skills they will utilize in later years to protect themselves from AIDS (and other

health threats as well—alcohol, driving dangerously, smoking, early sexual activity and so forth). The primary purpose of health education for children to age ten is to begin to establish the necessary foundations for these concepts and skills. The school district that already has such health programs in place—including trained and qualified teachers, an articulated health curriculum, and systems by which to involve parents and other representatives of the community in planning and implementing the curriculum—is clearly in the best position to integrate AIDS education easily and appropriately into the classroom.

Specific Content about AIDS That Young Children Should Understand

The Centers for Disease Control (CDC) has established guidelines for effective school health education concerning AIDS. (Centers for Disease Control. "Guidelines for Effective School Health Education to Prevent the Spread of AIDS." *Morbidity and Mortality Weekly Report* 37:suppl no. 8-2, 1987.) These guidelines provide sound parameters for teachers, administrators and parents wondering what children should understand about AIDS.

For early elementary grades, the CDC states that AIDS education "principally should be designed to allay excessive fears of the epidemic and of becoming infected." They suggest the following content areas be covered:

1. AIDS is a disease that is causing some adults to get very sick, but it does not commonly affect children.
2. AIDS is very hard to get. You cannot get it just by being near or touching someone who has it.
3. Scientists all over the world are working hard to find a way to stop people from getting AIDS and to cure those who have it.

In late elementary school, the CDC suggest content area that is quite a bit more detailed and includes the role of viruses in causing diseases; the existence of asymptomatic carriers for some diseases including AIDS; the methods of AIDS transmission (through sexual intercourse, sharing needles, and perinatally); the severity of the disease; and the fact that it is not casually transmitted.

In addition, we note that children mature at different rates, that the familiarity young children have with AIDS related concerns will depend to a large extent on family or community experience (whether many people in a community have been diagnosed with AIDS, whether a great deal of media attention has focused on the issue, whether family or friends have become ill with HIV-infection, and so forth), and that individual children or specific classes may have more detailed questions about AIDS. We hope that school administrators and parents will encourage teachers to respond to children's questions about AIDS appropriately as they arise, even if they fall beyond the guidelines suggested for early elementary level students; and that teachers will be supported with trainings in comprehensive health education and AIDS education specifically.

Classroom Examples

The classroom examples included here show teachers working within a sequenced, comprehensive health curriculum. In each class described, concepts or skills that relate to AIDS knowledge or prevention are being presented. In none of these classes, however, is a specific "lesson about AIDS" being offered. AIDS is handled within the context of the normal health curriculum and, therefore, is not sensationalized or blown out of proportion. Because of their expertise, teachers are able to handle this material appropriately so that children gain the necessary understanding; their questions are respected and responded to; and they do not leave the lessons with unnecessary anxiety or information beyond their comprehension.

A Kindergarten Class

Mrs. Thomas, a kindergarten teacher, has always felt a strong commitment to health education. She makes a particular effort to offer interesting and active lessons on health to her class. Her students respond enthusiastically—they are all very interested in being healthy, and they enjoy these activities thoroughly.

Earlier Foundation: In previous lessons, students were helped to conceptualize the definition of "germs" and to understand their role in causing disease. Mrs. Thomas had started with a simple lecture about germs and what they are.

Then she used a flannel board to tell the class a story about a child with a cold who had to stay home from school. In the next lesson, she used spray bottles filled with water to show the children how sneezes and coughs could spread colds. She also demonstrated that when the bottle nozzles were covered with a tissue, the spray did not spread. These activities all contributed to students' understanding simple concepts of germs, disease transmission and prevention.

The Lesson: After the current lesson, Mrs. Thomas expects her students will be able to:

1. Demonstrate the correct method of handwashing.
2. Explain how handwashing can help prevent the spread of germs and disease.
3. List some materials especially likely to carry germs, that should not be touched.

Mrs. Thomas reviewed the material from recent health lessons with her students, reminding them that while germs may cause disease, they are so small people cannot see them. She told them that they were going to do a special activity that would help them pretend they could see germs, and teach them about how to wash away germs on their hands.

A small amount of vegetable oil was poured into the palm of each student's hand. Mrs. Thomas showed the students how to spread the oil across the palms of both hands by rubbing them together. She then shook a little ground cinnamon on their palms to represent "germs."

The students were told to try to wash the oil and cinnamon off their hands using cold water. The cold water did not wash away the oil. Then the proper method of washing hands with warm, soapy water was demonstrated. Students washed their hands and the oil and cinnamon—just like most germs—were easily washed away.

Mrs. Thomas finished up her lesson with recommendations that the children wash their hands before meals, after going to the bathroom, and after playing if they look dirty. She reminded them that most of us put our hands in and around our mouths fairly often, which is one way germs on the hands can get inside the body. She also instructed the children not to touch certain things that were especially likely to carry disease-causing germs, including animal feces; things

in or around trash or garbage cans; or anyone else's blood. If a schoolmate or someone else was hurt or bleeding, the children were told to call a grown-up to help.

Comment: Mrs. Thomas' lesson made no mention of AIDS, but it did teach many ideas that are related to the conceptual foundation children must have to understand AIDS prevention when they are older. Basic principals of hygiene were reinforced. The students saw that personal efforts—in this case, hand-washing— could help protect their health and well-being. Through the earlier model of the spray bottle and the current demonstration of germs on hands, they learned that germs can be passed in different ways. In future lessons, they will gain a better understanding of their responsibility to protect others from disease by following good hygiene habits themselves.

The information about not touching blood is new in Mrs. Thomas' lesson, a section added recently because of concerns about the possibility of AIDS transmission. It is important to understand that the possibility of such transmission (that is, through one child touching another child's blood) is remote. No such cases have ever occurred. Nevertheless, for both children and adults, we believe it is a good hygiene guide to avoid direct contact with other people's blood.

In some areas, IV drug users have discarded syringes in public parks near children's play areas. In communities where children may come across used syringes, it would also be important to explain what syringes are and emphasize that they should never be touched. If a syringe is discovered by children, a grown-up should be called to the scene.

A Second Grade Class

Mr. Gutierrez, a second grade teacher, is helping his students examine communicable diseases, as prescribed in the health curriculum. He has a fairly typical range of students in his class. They are not unusually sophisticated as a group, but he has a few students who seem more worldly than the others.

Earlier Foundation: Mr. Gutierrez' young students have been involved in a health program that was carefully planned and sequenced through kindergarten and first grade. Many of this year's lessons have reviewed and reinforced

concepts introduced in these earlier grades. Recently, they have covered the concepts of wellness and illness, and they have discussed personal habits that promote good health. His class enjoys group learning activities, and students are active in discussions. Mr. Gutierrez often encourages students to contribute background facts to the lessons. In this manner, he can assess their understanding of previous lessons and consider their interests and needs in the current lesson.

The Lesson: Mr. Gutierrez' objectives for this lesson are that his students will be able to:

1. Define communicable disease.
2. Explain some ways that communicable diseases can be prevented.

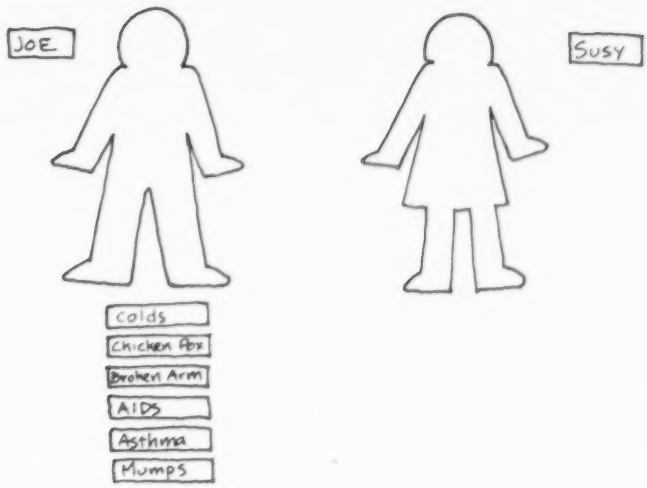
Mr. Gutierrez introduced the lesson by explaining that the class was going to talk about diseases that can be spread from one person to another. On the bulletin board, he had put two large cut-out figures. One was labeled "Joe," the other "Susy."

"Let's do some brainstorming," Mr. Gutierrez said. His students had used brainstorm techniques before and were familiar with them. One of the rules of brainstorming is that any contribution is accepted without judgment during the session. "What are some diseases or other ways that people can feel not well?"

Several students raised their hands. Mr. Gutierrez wrote the names of the diseases on the board as children were called on. "Colds," said Stephen. "Chicken pox," said Coleta. "A broken arm," suggested Teresa. "AIDS," called out Kirby. Mr. Gutierrez stopped for a split second—he hadn't expected this one. But he knew the rules of brainstorming, so he wrote it down. "Asthma," said Jordy. "Mumps," Chris offered.

"I think that's about enough for us now," said Mr. Gutierrez. Then he took out some large paper cards and wrote each disease on a card. "C-O-L-D-S. Colds. Stephen, will you pin this up on the board, under the cut-out of 'Joe'?" He had the children put up cards for each contribution.

When they were finished, the board looked like this:



"Now here's what we're going to figure out," Mr. Gutierrez told them. "Remember how we talked about the way germs can cause illness? Well, sometimes if one person has a germ, he or she can spread that germ—and the illness—to someone else. So let's decide which of these ways of being 'not well' can be spread from one person to another."

"Okay. 'Colds'—what do you all think about colds? Can one person with a cold give it to someone else?"

"Yes!" the students all agreed.

Mr. Gutierrez asked Shara to come take a piece of bright yarn he was holding. He showed her how to pin one end on the card that said "cold" and the other underneath "Susy."

"Good. Now what about chicken pox?"

"Yes," the students answered, and another piece of yarn went up.

"And a broken arm?"

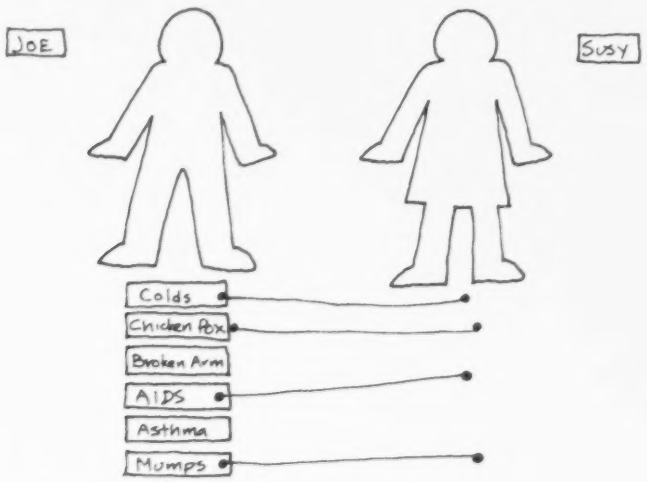
"No," the children answered.

"Okay. No yarn then, because Joe can't spread a broken arm to Susy. Now what about AIDS? Have you heard of AIDS before?"

Most of the students nodded. "Then you probably know that AIDS is a very serious disease. It's a disease mostly grown-ups get. Does anyone know if people can spread AIDS to someone else?"

The class was a little quieter on this one. "Yes," Kirby finally said. "People can spread AIDS." Two or three other students agreed.

"That's right," Mr. Gutierrez replied. Up went the yarn. When the full list was finished, the board looked like this:



Then Mr. Gutierrez talked about the meaning of "communicable disease." He discussed the concept until he felt the children had a good understanding of it.

"One of the very important things about communicable diseases," he added, "is that if you know how they are *caused*, you can figure out how to *keep* from getting them! This is an important way for us all to stay healthy. Let's see what we can figure out from our list here."

"Who can tell us how a cold might be passed? Shara?"

"Somebody coughs on you, or you drink out of their cup."

"That's right. So how could you keep from getting Joe's cold?"

"Don't drink out of his cup?"

"Yes! Okay—why don't you take *down* that piece of yarn by the word 'cold.' You know how not to get a cold."

Mr. Gutierrez continued the lesson. The children participated willingly and enjoyed being involved. They talked about chicken pox and the broken arm.

The next disease on the list was AIDS. Mr. Gutierrez didn't feel he would have brought up the topic of AIDS himself, but he believed that he had an obligation to respond to the material his students raised. He also knew he was acting within his school district's guidelines in doing so.

"So here's AIDS. Anyone know how AIDS is passed?"

"Yeah," said Stephen. "Sex and drugs."

"Yes, Stephen. If someone has the AIDS germ, and he or she has sex with someone else, that other person might get it. And if someone has the AIDS germ and takes drugs using a needle, and then shares that needle with someone else, that other person might get it." Mr. Gutierrez spoke slowly and carefully. This was more complicated than the other diseases they had discussed. "So how could someone keep from getting AIDS?"

"No drugs and no sex," said Coleta.

"Okay, Coleta. Why don't you take down that piece of yarn."

When Mr. Gutierrez finished the list with his students, he came back for a moment to AIDS. "It's important to remember that AIDS is not passed like colds or chicken pox. You can't get it from a cup. You can't get it from a cough. You can't get it from just touching someone. Unless people have sex or use drugs and needles with someone who has the AIDS germ, they don't need to worry about getting AIDS.

"And I think you will all want to know that doctors and scientists all over the world are working very hard to find a way to stop people from getting AIDS, and to help people who have it.

"We should move on to our next lesson now, but if any of you have any other questions about any of the things we talked about today, you can talk to me privately later."

Comment: Mr. Gutierrez' teaching style actively involves students in most of their lessons. He is comfortable with this approach, and his students respond well to it. There are times, however, such as with this lesson, that a student will bring up a topic that presents some difficulties. Mr. Gutierrez is accustomed to these experiences and has learned how to handle the situations by speaking simply and directly about the topics. He feels in this way he is able to minimize the possible complications, and he has not experienced further problems using this method.

Future lessons for his class will look more carefully at the reasons that sound health habits prevent disease. He will also introduce basic concepts of the immune system to the class—that is, that in addition to health habits, which are external ways of preventing disease, the body has internal ways of preventing or repairing illness. The children will explore the concept of "the body healing itself" after cuts and scratches, colds, chicken pox and so forth.

These future lessons need not mention AIDS directly, but again the concepts will lay a foundation to help children better understand AIDS information and prevention as they mature.

Teachers of young children should prepare themselves for the possibility that a student might bring up the topic of AIDS in the classroom or other settings. While teachers should not violate school or district guidelines in presenting AIDS-related material, they should be able to respond appropriately to such comments when they do arise. Mr. Gutierrez' direct and simple manner demonstrates one good way of handling a situation like this.

A Fourth Grade Class

Ms. Kim is the teacher of a fourth grade class. Her students come from a variety of cultural backgrounds and family structures. Several of her students live in large, extended families, while many others are in single parent homes. Still others split their time between the homes of divorced parents. The local neighborhood reflects this diversity of culture and family style as well, and active neighborhood organizations help build and maintain a sense of community among this diversity.

Earlier Foundation: Using their own families as examples, the class has explored some of the similarities and differences among families: in the various numbers of people included, in the places that parents and grandparents were born (they cover much of the globe), in the foods prepared, in which holidays are celebrated and how. Students felt a strong underlying message of support throughout these lessons. Each family is different, and there is no one "right" kind of family.

In recent classes, Ms. Kim had read her students a story about two families whose membership changed—new people moved in, others moved away, and babies were born. Then the students participated in a project over several days

in which they wrote and illustrated their own stories about an imaginary family of three members. Next the students added to their stories, each writing about an event that decreased the number in the family to two. Finally, they wrote their last chapters, which had the family increase in number to four.

The Lesson: Ms. Kim's current focus continues to be on ways that families change. At the end of this particular lesson, she expects her students to be able to:

1. Explain ways that families change by increasing or decreasing in size.

Ms. Kim began the lesson with a review of the concepts they had learned about families increasing or decreasing in size. Then she led the class in a discussion. "In your own family, or in the families in your neighborhood or of your friends, what kinds of increases or decreases have you seen?"

Debra excitedly told the story of her baby brother's birth a year earlier, and how she got to be present when he was born. Some of the other students were fascinated by the details of the birth. "Was there blood?" they asked. "How did something as big as a baby come out?"

Ms. Kim was not especially surprised. She knew that this particular lesson could bring up issues about birth and death. It was placed in the health curriculum at a point after students had covered basic facts of reproduction for just this reason. She explained to the students that a woman's vagina stretches during birth, and that it is normal to have some bleeding during the process.

"Are there other ways families you know have changed?" she asked.

Ezra talked about his cousin joining the army and moving to Germany. Then Michael described his mother's remarriage, and how he now had a stepfather and a "regular" father. Ryan said his grandfather had died, which made his mom very sad. "But I didn't really know him. He lived far away, and I only saw him once, when I was a baby. I don't even remember him, so it didn't bother me. But I didn't like to see my mom so sad."

Then Jennifer raised her hand. "One of my next door neighbors has AIDS and they say he is going to die any day now."

"AIDS!" said Ezra. "Yucch."

"Oh, you'll probably get AIDS too, 'cause you live next door," said Jorge.

"I will not!" retorted Jennifer.

"Will too!"

"What does he look like?" asked JoAnn.

"Is he gay?" asked Ryan.

Ms. Kim was interested in how the students reacted to Jennifer's comment. Members of her usually cordial class were beginning to tease Jennifer and order was breaking down. "Wait a minute here," she said. "Is this the way we have discussions in this class? Everyone talking at once?" The class quieted down. "It seems like many of you have questions for Jennifer or comments to make. Let's hear them one at a time."

No one spoke.

"No more comments? That surprises me. Jennifer's brought up a very interesting topic. I wonder, Jennifer, if this man is someone you know well?"

"Oh, I know him some. But he's been sick for a long time now, so I don't see him much any more. Sometimes, I go over with my mom when she cooks a meal for him and his roommate."

"His roommate is his *boyfriend*," Justin said, tauntingly.

"No he isn't, smarty," Jennifer snapped back. "His roommate is a *woman*, and they're just real good friends. My mom told me."

"Weren't you afraid to go over to his house?" asked Claire.

"No. It's a nice house."

"But weren't you afraid you would catch it?"

"No. You can't catch AIDS by going to someone's house. My mom told me. It's not like colds or something. It's different."

"So how do people get AIDS?" asked Jorge.

"You know. Through sex or something," Jennifer answered.

"No," said Sean. "I think you get it from using drugs. That's what I heard."

"What kind of drugs?" asked Claire.

"I don't know," Sean said. "Maybe marijuana? Something like that."

Ms. Kim spoke. "It sounds like we could use a short lesson about AIDS. You will learn more about this next year, in fifth grade, but I think you are all grown-up enough to understand some very important things right now."

"First, AIDS is a very serious disease. Many people have died from it. Second, as Jennifer said, it's not easy to get it. You can't catch it like a cold.

"But I still don't understand how people get it," said Claire.

"I'll explain," Ms. Kim replied. "First, someone must have the germ that causes AIDS—it's actually a virus—in his or her body before he or she can pass it on to someone else. You probably remember this idea from your earlier grades when you studied diseases.

"Now, if this person has sexual intercourse with someone else, the virus could pass between them, and the other person could get infected. Do you all understand this?"

"Yeah," said Jorge, "but what about drugs?"

"Well, if this person with the AIDS virus used IV drugs— using a needle to take the drugs—and shared that needle with someone else, the second person could become infected. You see, the virus lives in blood. When people share needles, a little blood is usually left on the needle." Ms. Kim drew some diagrams on the board to explain this better. "When you go to the doctor or the health clinic, you don't need to worry if you're getting a shot there, because those needles are *sterile*—there are no germs on them—and they are used only once and then thrown away."

"Why would anyone have sex or shoot drugs with someone who has AIDS? They're so sick. I think that's weird," Harley commented.

"Most people who have the AIDS virus don't look or feel sick. You can't tell just by looking that someone is infected. And that person might not even know the virus is in his or her body."

"I thought that babies could get AIDS," Claire said.

"Yes, Claire. Sometimes, a woman who has the AIDS virus in her body gets pregnant. Then her baby might catch the virus from her before it is even born."

"I heard about a kid our age who had AIDS," said Ryan. "Did he have sex, or use drugs? He's only ten."

"I think this was probably a boy who had received a blood transfusion. Some blood used in transfusions was infected with the AIDS virus. Several years ago, scientists found out how to check the blood, so now it is safe to have a transfusion."

"What's a transfusion?" asked Rebecca.

"If someone is very sick or injured very badly, he or she might lose a lot of blood. Doctors can take a little blood from a healthy person and put it into the body of the sick person to help him or her heal."

The class began to grow quiet. "Oh, I see that it's about time for recess. Well, our lesson on families has been very interesting, and now we have talked a lot about AIDS too. If any of you have other questions about AIDS, either today or later on, I hope you'll ask me. Remember that you can ask your parents these questions, too."

The bell rang, right on cue. "Class dismissed," said Ms. Kim.

Comment: Ms. Kim took advantage of a classic "teachable moment." Her class showed a significant interest in the topic of AIDS. Initially, she listened to their comments for a few minutes to get a further sense of their level of knowledge. As she explained AIDS to them, she moved gradually from one point to another, responding to the questions her students raised. The entire process was relatively easy for Ms. Kim, and clear for the children, because they had several essential concepts in place already: health and illness; communicable disease; sexual intercourse; IV drug use; and pregnancy (in discussing perinatal transmission). Future lessons in her class will discuss community well-being and how to help others. In these lessons, Ms. Kim may again raise the topic of AIDS to reinforce the need for compassion towards persons affected.

Chapter 8

Trouble Shooting: Anticipating Problems that Might Come Up in Discussing AIDS with Young Children

It is natural to worry that difficulties might arise in discussing the topic of AIDS with young children. The most common problem adults experience is their own sense of awkwardness when a child surprises them with a question and a graceful or appropriate answer does not immediately come to mind. This is an easier problem to deal with—you take a breath, say, "That's a good question. Let me think about it for just a moment," and then give the best answer you can!

We mention here a few other problems that might arise, along with some suggested responses.

1. What if neighborhood children are playing with my kids, and they ask me questions about AIDS? Should I refer them back to their parents, or answer the question?

This depends on your particular neighborhood and what you believe these parents would like, but generally we recommend you do both things. First, answer the question in the most appropriate and matter-of-fact way you can (remembering the guidelines we mentioned in Chapter 2: *Things to Keep in Mind*). Then, suggest the children talk over these things with their own parents. Finally, speak with the parents yourself and let them know the topic came up, and how you responded.

2. If students in my second grade class ask me questions about AIDS, I wonder how parents will feel about my discussing this topic with their children.

In school settings, we recommend you use the same guidelines for talking about AIDS that you would use with other sensitive topics like sexuality, drug use, death, and so forth. We hope teachers are encouraged to discuss such topics when they come up in the classroom, and that they receive training to assist them to do so skillfully and appropriately. We also believe parents should be informed about curricula being used with their children and have an opportunity to familiarize themselves with how the class is being taught if they wish.

3. What can I do in a classroom or group setting when one child has more sophisticated knowledge about AIDS or sexuality than the other students, and that child asks an explicit question requiring an answer that seems too advanced for the other kids?

One approach many teachers use is to say something along these lines: "That's a complicated question and I don't know that your classmates will be interested in taking a lot of time to answer it. Why don't you come up to my desk in the next recess break and we can talk it over." Then you can answer the question privately with the student. You may also want to refer the child to his or her parents for further discussion of the issue. In some schools, a school counselor is also available to speak with children who have sensitive questions.

4. What can I do in a classroom setting when a child asks a question, and sharing the answer clearly violates the guidelines of our school concerning discussions of sexuality in classrooms?

You can be forthright in explaining why your response is limited. "In this school, we have rules about what we can talk about in classrooms. One of those rules says we cannot talk about certain sexual matters. This question you raise is a good one, but because of these rules, I'm not able to give you the answer. I'd like to suggest you ask your parents this same question—I think they will have a good answer for you."

Another alternative acceptable in some schools is to discuss the answer with the child privately. You could use the same sort of approach suggested in

question three, or you could say, "This is not something I am allowed to discuss in front of the entire classroom, but if you would like to meet with me during the recess, we could talk about it privately." We would still recommend referring the child to his or her parents as well.

Finally, if you are able to contact the parents and explain these events, they may appreciate being forewarned of the child's interest and be able to better prepare their own answers.

It might also be a good idea to keep your administration, advisory committees, and so forth, advised of the kinds of questions your students are asking. If such questions are common, it may help justify efforts to expand the range of topics that *can* be discussed in a classroom.

5. We have had experiences with students who seem to have a lot more sexual information—and misinformation—than most children their age, and eagerly share this with other students. I wonder what we should do if something similar happens concerning AIDS—if we have a child who talks about it a lot with other children, is not always accurate in what he or she says, and maybe raises a lot of anxiety for the others.

We have to be realistic about the fact that children are *constantly* sharing information with one another about all kinds of things, and much of it is inaccurate. We cannot stop this from happening, nor would we want to—it is developmentally appropriate that they do such things. It is also another *good* reason for us to provide accurate information in the classroom itself, whether that be about AIDS, sexuality, or any other topic.

This becomes more of a problem, however, if a particular child is causing difficulties with others because of his or her behavior. If other children are upset or anxious because of what is happening, some adult intervention is probably called for. If the child's behavior seems out of character and extreme, other events may be going on in his or her life related to the problems. You might consider such actions as having a private talk with the child, setting up a parent conference, or referring the child to a school counselor.

When the disruptive behavior is of a particularly sexualized nature (touching other children's genitals, mimicking sexual postures with other children, and so forth), you would certainly need to consider the possibility that the child is being sexually abused. Such cases should be discussed with local Child

Protective Services or a professional child counselor familiar with issues of child sexual abuse.

6. What can I do if one of my young students (or my own child) seems to be obsessed with AIDS, or repeatedly asks a question and is not satisfied with the factual answers given?

There are a number of reasons why a child might behave in this fashion. It may be that he or she is especially anxious by nature, and that AIDS has simply become the focus of a more generalized anxiety. It is also possible that someone close to the child is diagnosed with or at risk for AIDS, and these questions represent the child's attempt to understand an event of major proportions in his or her life. A child may also fear being at personal risk for some reason. Our greatest concern in this instance would be the possibility that the child is being sexually abused.

Whenever a child seems very focused on AIDS for some time—a few weeks or more—caretaking adults will need a better understanding of what is going on. A teacher or parent may want to speak with the child individually to try to discover more about the child's anxieties. An evaluation by an experienced child therapist is called for if the problems do not resolve in short order.

7. Some of the children in my after-school recreation club were making derogatory comments about people with AIDS. How do you suggest I handle this?

This behavior is not unusual. We know that children will make jokes about people they perceive to be different from them. This may include racial and religious slurs, ridicule of the elderly and disabled, crudities about homosexuals, or harassment of schoolmates who are being scapegoated for one reason or another. When children make such comments in the presence of adults, we believe strongly that firm limits are called for— "These kind of remarks are not acceptable when you are participating as a member of this club. You may not say that here." It may also be useful to discuss the issue further with the children. Do they understand what AIDS is? Do they have questions about it? and so forth.

We understand that many children will continue to engage in such behaviors. However, our limits send a clear message that it is unacceptable to do so in public settings or polite company. We demonstrate our belief that all

people deserve respect. We set a standard of tolerance and compassion for others that can be emulated by young children as they mature.

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Other problems may arise as you discuss AIDS with young children. We repeat here a message you have read elsewhere in this book—the issues that AIDS raises are not new to us. The same sound principles that have been successful in the past when dealing with difficult issues will work when you are talking about AIDS as well.

Chapter 9

How to Do It Right: The School with HIV-Infected Students or Staff

We have all heard of schools and communities struggling over the issue of children with AIDS. We carry images of communities alarmed, schools facing boycotts, and children hoisting placards expressing their parents' concerns about casual transmission of AIDS. We hear of legal battles, lawsuits and court orders. We sense the terrible turmoil this circumstance brings to a community.

It may be surprising to learn that in a number of communities throughout the nation, schools dealing with this very issue have done so calmly, smoothly and successfully. In such places, there have been no boycotts, no court involvement and minimal alarm or protest among parents. In fact, in the best of them, the students with AIDS, if they are publicly identified, are cared for, supported and defended.

It is unfortunate that press reports commonly tell only of the communities that falter in this endeavor. It is easy to get the impression that this level of controversy is inevitable. Thankfully, we now have a number of examples that show us otherwise.

We want to offer some general suggestions for elementary schools who have a known student or staff member who is HIV-infected on the campus. We will briefly review some approaches for preparing and working with the larger school community as well as with the students themselves. For references that treat this full issue in greater depth, see the Further Resources section.

Groundwork

If a comprehensive school health program along the lines recommended in this book is in place before a member of the school community is diagnosed with AIDS or HIV infection, the foundation for discussing the issue will already be in place. Young children will probably be familiar with the word "AIDS," and if so, they will have a sense that it is a serious disease. They will know it is not casually transmitted. If a good community program educating adults about AIDS has been carried out, the children's knowledge can be reinforced at home by parents. Having this knowledge about HIV infection and confidently believing it is the most important factor for a community coping with an HIV-infected individual in a school setting.

It is important to have policies addressing these issues in place before situations arise, and to have carried out a campaign to inform parents, teachers and the larger community of what these policies are. Most policies state that, while circumstances will be judged on a case-by-case basis, the most normal and unrestricted setting possible will be advocated for an HIV-infected child, and HIV-infected staff will continue to work as long as they are physically and mentally capable of doing so. These standards are consistent with the recommendations of the Centers for Disease Control, the American Academy of Pediatrics and current trends in legal decisions. Many school districts also state explicitly in their policy guidelines that the identity of an HIV-infected student or staff member will be protected and that the names of these individuals will not be disclosed to teachers or parents.

School staff should be trained in appropriate methods of handling any body products (blood, urine, feces, vomitus), and these practices should be put in place, again *before* there is an identified HIV-infected individual on campus. This means that latex or vinyl gloves are used when cleaning soiled areas; that such areas are disinfected with a 1:10 solution of household bleach (one part bleach mixed with nine parts of water); and that hands are washed in hot soapy water when the task is completed. Nurses or teachers should wear latex gloves when providing first aid. The likelihood of HIV transmission occurring if such practices are *not* followed is remote, but these procedures represent good general hygiene in any case and can prevent the transmission of other diseases as well.

If and When It Happens: Informing Teachers, Parents, Students and the Community at Large

In some large cities known to have a high incidence of HIV infection, school districts have issued statements to the effect that "it will inevitably happen that we have HIV-infected staff or students at our schools. It may have (or has) happened already. We have no intention of making announcements to the press, parents or students as such cases arise. Our policies regarding HIV-infected students are on record, and may be examined by any interested parties."

In other settings, this approach may be less practical. While we fully expect to see HIV-infected children in New York City, New Jersey, Los Angeles or San Francisco, there is a greater element of surprise when this happens in some other areas. It may be more difficult to protect the identity of the affected individual in these areas. If a community has only one elementary school, and one student in that school has been hospitalized with a serious, unnamed illness, and word gets out that there is an HIV-infected student attending the local elementary school, people will draw reasonable conclusions about who this child is.

Many approaches that will meet with success in this situation are possible. We would like to present the story of a hypothetical community making a series of good choices in dealing with the presence of an HIV-infected child in one of its schools. The steps we describe here are based on actual practices followed by several different communities that faced such a circumstance and had a successful experience with their students, school personnel, parents and the larger community. None of these communities did all the things we describe, but we hope our story suggests a good range of possibilities for schools or community programs that may face similar situations in the future.

Our Imaginary Community

Our imaginary community is a medium-sized one, with several elementary and middle schools and two high schools. A comprehensive K-12 school health program has been in place in the district for a number of years. Specific lessons on AIDS have been taught in the middle and high schools. Simpler, AIDS-

specific lessons are also being offered to fifth and sixth graders. For younger children, AIDS has been presented as an integrated part of topics such as illness and wellness, community health, disease prevention and so forth.

Community education on AIDS has also been provided by the local health department. They have offered education at a number of events including community club meetings, the county fair, special forums for businesses, citywide health fairs, local health clinics, and through the adult education program at the community college. Physicians in private practice have also been invited to trainings and may subscribe to a free quarterly newsletter addressing issues of AIDS information and treatment.

Policies concerning school attendance by HIV-infected students were put in place the previous year. These policies support the full participation of any such student in school activities as long as such participation is appropriate for the child. Parents and the larger community have been informed of the school district's policies.

What Happened

A principal at one of the elementary schools was informed by parents of one of her students that their son had been diagnosed with AIDS. Following prearranged guidelines, the principal informed the superintendent, who assembled the school board at a special meeting to discuss the issue. The superintendent felt strongly that the school community would need to be told directly about the presence of the HIV-infected child in the schools. He believed if the district were not forthright about the matter and it later became known that they had withheld information, they would lose tremendous credibility in the eyes of the community. As a result of this particular meeting, the board put together a packet that included a cover letter from the superintendent explaining the situation, information about AIDS transmission and a copy of the school policy concerning HIV-infected students.

A meeting was held with a small group of teachers who were informed of the circumstances and asked to review the materials in the information packet. A local physician knowledgeable about AIDS also spoke with the teachers, answering their questions and responding to their concerns. The packet and the discussion were evaluated by the teachers: Did they find the materials helpful?

Did they support the board's decision to continue the enrollment of a student with AIDS? Did their questions seem adequately addressed? Was their physician speaker credible and reassuring?

The response was positive, so the packet was distributed to all teachers and parents in the district, along with an invitation to attend an informational session on AIDS for parents, set for an evening the following week. An upcoming date was selected on which students in the district would be taught a special class on AIDS, and parents were notified of these planned sessions as well. It was suggested that they might want to discuss the issue with their children before the class itself was taught, and guidelines for parent-child discussions on AIDS were included in the packet.

Meanwhile, contacts with the local media had been carefully planned as well. The media agreed not to release the news until after the parent packages were sent. Their reporting was factual without being incendiary. The emphasis of news stories was on the community's concern for the family affected and their willingness to support one of their own in time of need.

Contact was also made with representatives of local independent and religious schools. The sense of community partnership continued—these schools, aware of the circumstances, set up educational sessions with their teachers and parents. There was a unified sense throughout the district that the correct course had been chosen by the public schools.

The parent meeting was well attended. The physician speaker, having been carefully evaluated by the teacher's group, was well received by the audience at the meeting. The superintendent also spoke, focusing especially on the role of the community, their need to support this family in distress, and their opportunity to teach their children some important lessons about family, loyalty and community. The audience was divided into small groups to discuss personal concerns, and they were led in exercises to help them prepare to talk about AIDS with their children.

Local religious leaders were also contacted. They were, of course, well aware of the circumstances since they had read about this in the newspaper, and some of them were also parents of district students. The school district invited their collaboration in this effort to inform and strengthen the community. Many of them presented sermons stressing tolerance, compassion and the need to be

well informed on the issue during the week following the parent meeting.

Teachers were also given trainings on how to present materials about AIDS to their students. Mentor teachers helped develop special lesson plans for each school level: early elementary, later elementary, middle and high school. These plans were simple in nature and were integrated as a natural part of the normal health curriculum. Teachers acknowledged the fact that an HIV-infected student would be attending a district school and explored students' reactions to the news.

In all of this effort and discussion, the actual identity of the diagnosed child was never released. In time, the family became identified to many in the community because they, of their own choosing, informed friends and others. The community had been well educated at that point and, for the most part, the parents and their son were supported and helped by others. The superintendent's carefully designed plan, aimed at offering correct information and building community cohesion, was successful both at the broader community level and in the more personal realm of this family's experience.

What Was Taught to the Early Elementary Students

In our hypothetical community, the early elementary students had already been provided a conceptual foundation about healthful living and disease prevention in the normal health curriculum. They were familiar with the differences between illness and wellness. They knew that some diseases are contagious while others are not, and they knew there are ways to prevent some diseases. AIDS had been mentioned in passing in a number of the classrooms as children raised their own questions during health discussions.

Teachers of these students were given a special training so that they had a sound general background on AIDS information and a sense of how to answer young children's questions about AIDS. School guidelines for discussions of sensitive topics like sexuality and drug use were reviewed. A class discussion outline, included below, was distributed and reviewed. Because children at this age do not have long attention spans, the discussion sessions were designed to last only 20 minutes or so. If classes were very interested in the topic, the teachers were encouraged to bring it up again on a later day in the week.

Class Discussion Outline

I. Review.

Review basic information about diseases and disease prevention.

II. Introduce topic.

"There have been some news stories and special parent meetings in our town lately concerning a student in one of our schools who is ill. Have any of you heard about this? Some of you may have talked about it with your parents. What is the illness this student has?"

III. Develop discussion.

"Yes, it's AIDS. I wonder what kinds of things you have heard about AIDS."

IV. Answer questions.

A. Respond to questions and concerns raised by students. (Responses can be based on the answers given in this book in Chapter 4: *What Are Children Asking, and How Can You Answer Them?)*

B. Emphasize that people are not at risk through casual transmission.

V. Conclusion.

A. No risk through casual transmission.

B. If someone is ill, we should do our best to help them and be kind to them.

C. Discuss: What are some ways we can help people who are sick?

1. Send cards.
2. Call on the phone.
3. Visit.
4. Take flowers or other gifts.
5. Give them their favorite foods.
6. Help with chores if a person can't do them him or herself.
7. Other ideas?

VI. Exercise.

A. Students draw a picture showing a way to help out someone who is ill.

B. Students take pictures home and discuss them with parents. Ask parents to help students write a description of their picture and what it shows.

C. [Optional] Post pictures and descriptions in the classroom, or in other locations throughout the school or community.

The teachers of young children had a meeting after this session to discuss their own and their students' reactions to the lessons, get any necessary help or advice on difficult questions, and evaluate the success of the program. They felt for the most part that their students had been interested and concerned. Many also felt that the lessons had helped decrease any anxieties about AIDS and increase their sense of community cohesion and involvement.

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While we cannot guarantee that a similar course of events will always meet with success, we know that these sorts of approaches have been helpful in some communities. We hope this sense of an "ideal" setting will remind us that better outcomes are possible and worth striving for.

SECTION 2

BACKGROUND INFORMATION

Chapter 10

AIDS Information: Answers for Adults

This chapter covers quite a bit of information about AIDS. Reading it will give you a general understanding of the disease and the epidemic. Having this foundation of knowledge will help you determine how to best answer young children's questions about AIDS.

Much of this information is too sophisticated for young children and we are not suggesting you use these answers with them. Please see Chapter 4: *What Are Children Asking, and How Can You Answer Them?* for examples of answers to children's questions.

Description and Epidemiology

What is AIDS?

AIDS is a disease that breaks down a part of the body's immune system, leaving a person vulnerable to a variety of unusual, life-threatening illnesses. It is caused by a virus. This virus may also infect the brain, causing a variety of neurological problems.

Why are people concerned about AIDS now? Why haven't we heard about it before?

AIDS was not recognized or described as a disease until 1981. Tracking of AIDS only began when doctors had seen enough of it to recognize that they were faced with a serious, previously unknown disease. In 1981, 316 people in the United States had AIDS. Five years later (by August, 1986), over 23,000 cases were reported here. A tremendous growth in the rate of the disease has continued and today we have over 60,000 reported cases. This is alarming, and scientists, health professionals and the general public have all become extremely concerned about it.

Where did AIDS come from?

The exact origins of AIDS are not known. Either it is a new human disease that developed recently, or it is a disease that was until recently isolated in a particular geographic group of people.

The prevailing scientific opinion now is that the virus originated in Africa. A particular kind of monkey, the African green monkey, is known to carry a virus quite similar in structure to the human AIDS virus. The best scientific guess is that at some point in time, as a natural part of the process of all living organisms, there was a chance mutation of one of the simian (monkey) viruses, which made it possible for the virus to cross the species barrier from monkey to human. While mutations at the cellular level are fairly common, this particular type of mutation would be very unusual.

In certain areas of Africa, the green monkey is considered a food delicacy. Possibly through ingesting some uncooked organs, or through an accidental cut while preparing a carcass, the first human was infected. The disease may have begun in this simple, quiet manner, spreading to others from this point through sexual intercourse and shared needle use.

We want to note that many African government representatives are sensitive about this view, understandably, since it is often set forth in a manner that seems to blame Africa for the appearance of the virus. While scientific events are not themselves racist, observations and reporting of them may be so. It is important to remember that no one person, nation or population is responsible for the development of AIDS, and we must all share the responsibility for stopping the spread of the virus.

What is the AIDS virus? What is HIV?

The AIDS virus is one of a special kind of viruses called retroviruses. When a person is infected, the virus takes over certain cells in the immune system, destroying the cells' disease-fighting capabilities. The virus then uses the reproductive mechanisms of the cell to reproduce more virus. It has been difficult to control retroviruses.

The AIDS virus has been given a variety of names by different researchers, including HTLV-3, LAV, and ARV. In 1986, an international panel suggested it be called HIV—Human Immunodeficiency Virus. This is the name commonly used now.

The AIDS virus is also a fragile virus. It does not live long or well outside the human body. It is easily killed with a 1:10 solution of bleach and water, and can be washed from hands or skin with regular soaps.

There have been reports of AIDS virus surviving outside the body for periods of several days. In these studies, massive concentrations of virus were used. The actual concentration of the virus in blood or semen is *many* times less, so in any natural biological state the virus will *not* survive outside the human body for more than a few hours at most.

How do people get AIDS?

People do *not* get AIDS in day-to-day, casual contact with family, friends, acquaintances, workmates or the population at large.

The virus that causes AIDS lives in certain body fluids, especially blood and semen. People become infected with the AIDS virus by having *very* intimate, *very* direct contact with the semen, vaginal secretions, blood or feces of someone else who is infectious. The known courses of transmission include:

1. Sexual intercourse (vaginal, anal and oral intercourse).
2. Shared use of needles for IV-drug use. We are also concerned about the possibility of other needle use transmitting AIDS—e.g., nonprofessional tattooing or ear piercing among friends.
3. Infected mothers passing the virus on to a fetus.
4. Transfusion of blood or blood products infected with the AIDS virus (blood donations are now screened for the AIDS virus, and transfusion-related AIDS will be quite rare in the future).

Finally, a small number of health care workers who have had unusual exposure to patient blood have become infected. For example, a lab technician, because of an equipment malfunction, was splashed in the eye with copious quantities of AIDS-infected blood. She has subsequently become infected herself. Instances such as these, while rare, remind health professionals to follow infection control guidelines carefully.

Can people get AIDS through oral sex?

There has been some controversy about transmission of the AIDS virus through oral sex. While it seems that oral sex is not the most efficient means of transmitting the AIDS virus, a small number of people have become infected and report engaging only in oral (not vaginal or anal) intercourse. The Centers for Disease Control (CDC) is convinced by its data that oral intercourse *is* a means of transmission. (The CDC is a federal agency that investigates the spread, treatment and prevention of AIDS and other diseases.)

While the risk of transmission via oral sex may be much lower than through vaginal or anal intercourse, AIDS is a very serious disease. We consider oral intercourse with an infected individual (or with someone whose infection status is unknown) *unsafe.*

Can the AIDS virus be transmitted through other "body fluids"?

The AIDS virus has been found in blood, semen, urine, vaginal secretion, spinal fluid, tears, saliva and breast milk. Of these, *only semen, vaginal secretions, and blood are implicated in transmission.* There are also a few cases in which babies have contracted AIDS through infected breast milk. Feces are also considered a risk because they may carry blood.

People are naturally concerned about some of the other fluids—contact with tears or saliva is much more common in day-to-day life. Evidently, these other fluids do not carry a strong enough concentration of the virus to cause infection, even in the unlikely event one's blood system were to come into direct contact with them. In all reported U.S. cases so far, there is not a single case of transmission of the AIDS virus by saliva. Occasional news reports of such transmission, in the U.S. and elsewhere, have all turned out to be incorrect.

So far, the AIDS virus has not been detected in sweat. Even if it is found here at a future time, sweat, like tears or saliva, is not implicated in transmission.

What is the risk of heterosexuals contracting AIDS?

Anyone can contract AIDS if he or she is exposed to the virus through unsafe sex or the sharing of IV needles.

Most experts do not consider it likely that AIDS will spread as rapidly among heterosexuals as it has with gay men because heterosexuals generally have fewer sexual partners. A small number of well-informed researchers, however, feel heterosexuals should be more aware of and alert to AIDS risks than they have been. AIDS can be spread by vaginal intercourse, and there are cases of male-to-female and female-to-male transmission. Those at highest risk are people with multiple sexual partners in areas where the

disease is already widespread. In some countries, virtually all of those affected with AIDS are heterosexuals.

For most U.S. heterosexuals, the risk of contracting AIDS today is small. The judicious use of safer sex practices (along with not sharing IV needles) can keep the risk small in the future.

Can lesbians get AIDS?

A few cases have now been reported of sexual transmission of the AIDS virus between lesbians. We recommend that lesbians consider partners' sexual histories and any past IV-drug use. If there is a possibility of risk, they should practice safer sex. Like everyone else, lesbians are also susceptible to AIDS infection through IV-drug use or unsafe sexual contact with infected men.

Can people get AIDS from insect bites?

A considerable amount of study has been focused on this subject, and most of the scientific community is well-convinced that this is not a mode of transmission. It is important to remember that while mosquitoes do withdraw blood from people, they do not exchange blood between people.

A careful look at epidemiology makes this clearer. Malaria is a widespread disease in Africa that *is* spread by mosquitoes. The insects first ingest the parasite that causes malaria by feeding on an infected person, then transmit the parasite through their saliva to another person several days later. People of all ages are infected, including children and elders who may not be sexually active. AIDS, on the other hand, is a disease spread by shared needle use and intimate sexual contact, and the people of both Africa and the U.S. who are infected or diagnosed with AIDS fall into specific categories of risk. They do not represent the more general population of individuals bitten by mosquitoes.

A community in Florida, Belle Glade, has had a very high incidence of AIDS. Many of the residents are farm workers, who might receive hundreds of mosquito bites a day. Studies there specifically sought to determine

whether mosquitoes were implicated in transmission of AIDS. The studies showed that the residents of Belle Glade infected or diagnosed with AIDS have the same kinds of risks other people have had—sharing needles in IV drug use, or sexual contact with persons at risk (primarily heterosexual contact in these cases). Those with high incidences of mosquito bites without other risk factors did *not* become infected.

You can see this as well if you consider the example, in the U.S., of children between the ages of about four and twelve who frequently play outside at dusk in areas infested with mosquitoes. While we may see children with dozens of mosquito bites, we do not see cases of AIDS or HIV infection in this group except when a child has other risk factors (boys with hemophilia, for example).

What is the breakdown of risk factors among people diagnosed with AIDS in the United States?

Remember that *anyone* infected with the AIDS virus *might* develop AIDS.

Though people in the United States diagnosed with AIDS usually fall into one of several risk categories, it is *behaviors*, not membership in any particular group, which will put someone at risk for AIDS or HIV infection today.

In May, 1988, the breakdown for source of infection in adolescents and adults with AIDS in the United States was as follows (while absolute numbers in these reports change weekly, the percentages represent more general trends and will not be likely to change significantly for some time):

Population	**# Cases (May 1988)**	**% Total***
Gay or bisexual men	38,371	63
IV drug users	11,256	19
Gay male & IV drug user	4,489	7
Hemophilia/coagulation disorder	597	1

Heterosexual contact	2,489	4
Blood transfusion	1,492	2
Undetermined	1,929	3

*Total not 100% due to rounding

Symptoms, Natural History and Range of Infection

What happens to the immune system when someone is infected with the AIDS virus?

The immune system is complex. In studying AIDS, medical researchers are beginning to understand more about it.

Basically, the body of a person infected with the AIDS virus may lose the ability to fight off certain infections that people with healthy immune systems can combat successfully. For instance, *Pneumocystis carinii* pneumonia (PCP), a common and serious infection in persons with AIDS, is caused by a one-celled organism that is all around us. Most of us have already been exposed to this organism many times throughout our lives. The body's immune system recognizes it and eliminates it without our ever becoming ill. For people with AIDS, the immune system may recognize the parasite, but the immune response is damaged so the body is unable to fight the infection, and the person becomes ill. The kinds of diseases that infect a person with this kind of immune problem are called "opportunistic infections."

What is it like to have AIDS?

One of the striking qualities of this disease is the tremendous variation in how it affects different people. There are people who have been living with an AIDS diagnosis for over six years and who are still working, energetic and productive; others may die within a few days or weeks of diagnosis. Some people are fatigued or very sick throughout the course of the disease. For others, periods of health alternate with periods of illness.

There are people with AIDS who are severely disabled and there are those who are in excellent physical condition. A group of San Francisco people with AIDS runs the 7-1/2 mile Bay to Breakers race every year!

At the onset of illness, most people report several of the following symptoms:

- Unexplained, persistent fatigue.
- Unexplained fever, shaking chills, or drenching night sweats lasting longer than several weeks.
- Unexplained weight loss greater than 10 pounds.
- Swollen glands (enlarged lymph nodes, usually in the neck, armpits or groin), which are otherwise unexplained and last more than two months.
- Pink to purple flat or raised blotches or bumps occurring on or under the skin, inside the mouth, nose, eyelids or rectum. Initially, they may resemble bruises but do not disappear. They are usually harder than the skin around them.
- Persistent white spots or unusual blemishes in the mouth.
- Persistent diarrhea.
- Persistent dry cough that has lasted too long to be caused by a common respiratory infection, especially if accompanied by shortness of breath.

At first glance, some of these symptoms seem much like common signs of cold, flu, etc. The key is that they are severe in nature and last over a significant period—several weeks or more—during which time usual colds or flus would have resolved. Even if symptoms are severe and long-lasting, many of these problems may actually be caused by a variety of other illnesses. AIDS CANNOT BE SELF-DIAGNOSED. Anyone concerned with symptoms should see a physician familiar with AIDS.

What is the difference between HIV infection, ARC and AIDS?

Anyone infected with the AIDS virus has HIV infection. Such people fall into one of three categories:

1. Some people infected with the virus do not appear or feel ill. They *are* able to pass the virus on to others through unsafe sexual contact or the sharing of needles in intravenous drug use. These people are said to have *asymptomatic HIV infection*. Sometimes they are called *asymptomatic carriers* because they carry the virus without showing symptoms.
2. Some people infected with the virus develop mild to severe symptoms caused by the infection, but do not meet the criteria set by the CDC for an AIDS diagnosis. These people are said to have *AIDS-Related Complex*, or *ARC*.
3. Finally, some people who have HIV infection and symptoms of illness *do* meet the criteria for an AIDS diagnosis, and so have AIDS.

Why are people with HIV infection classified in these different ways?

In 1981, when AIDS was first described, we did not know what caused the disease and we had no way to test for infection. The CDC developed a definition of AIDS so it could monitor the number of cases occurring. Their scientists described AIDS by listing common symptoms of the disease in its most serious state. These were the cases coming to the attention of physicians. This definition said a person had AIDS if he or she had no underlying cause of immune system problems, but did have one or more of the following: (1) Kaposi's sarcoma (KS), (2) *Pneumocystis carinii* pneumonia (PCP), or (3) other opportunistic infections (OI). (These diseases are explained further below.)

This definition left out a lot of people affected by HIV infection, but it was several years before the broader range of HIV infection was understood. The CDC has made a few changes in its definition since 1981, but feels that broadening the definition too much will invalidate the data they have already collected on AIDS.

There are some difficulties with this situation. For one thing, people with ARC often are not eligible for the same benefits and services as people with AIDS, though they may need such assistance. For another, the uncertainties of having ARC are many (Will I die? Will I be able to continue working? Will I recover my health?), and numerous studies have shown people with ARC experience greater anxiety than people with AIDS or those who are well. Finally, the official CDC surveillance of the disease caused by the AIDS virus only counts a small percentage of those actually affected, and the concerns of people with ARC are often neglected in health policy and research planning.

The CDC updated its definition of AIDS in August, 1987. People showing signs of direct brain infection with the virus and those who have "wasting" disease (severe and persistent loss of weight associated with AIDS virus infection) are now also considered to have AIDS. In 1986, a four-tier system of classifying all stages of AIDS infection was developed. Many people working in the AIDS field now talk more generally of people having HIV infection rather than making many distinctions between "AIDS," "moderate ARC," "severe ARC," "mild AIDS-related symptoms," and so forth.

What are the illnesses that affect people with AIDS or HIV infection?

The manifestations of HIV infection can vary widely from person to person. The range of infections seen is quite broad, with people being affected by fungal, bacterial, protozoal and viral diseases as well as some cancers. The two diseases we hear about most often are Kaposi's sarcoma and *Pneumocystis carinii* pneumonia. Kaposi's sarcoma (KS) is a cancer of the cells that line certain small blood vessels. People with KS develop purple lesions, which may appear on the skin where they can be seen or internally where they cannot be seen. In time, the number of lesions will usually increase and they may grow in size. As the disease progresses, complications may develop because of the number and size of lesions.

Pneumocystis carinii pneumonia (PCP) is the most common opportun-

istic infection seen in people with AIDS. It is caused by a protozoan, a microscopic organism. People with PCP usually become quite ill at the time of diagnosis, with fatigue, weight loss, fevers, dry cough and difficulty breathing. Often PCP requires hospitalization. This disease can be treated. As with other AIDS-related diseases, successful treatment of PCP does not cure the underlying immune problems. In time a person may again be affected by PCP or other opportunistic infections.

Many people with HIV infection also suffer from infections that can lead to confusion, loss of memory, poor motor control, inability to speak clearly, seizures, or other manifestations of dementia. These problems may be caused by direct HIV infection of the brain, or by diseases such as toxoplasmosis or cryptococcal meningitis.

Other illnesses seen are either very unusual diseases rarely diagnosed in anyone who does not have HIV infection, or more common human illnesses that appear in unusually severe forms. For example, a person with AIDS might have a thrush infection (Candida) which is not limited to the mouth but spreads throughout the esophagus and intestinal tract. An HIV-infected individual might develop a herpes simplex infection that spreads well beyond the usual mucous membrane sites for herpes (mouth, genitals) over other skin surfaces, in spinal fluid, or in the lungs.

How long can a person be infected with the AIDS virus before being diagnosed with AIDS?

Estimates of the incubation period for AIDS have changed as research continues and we have more experience with the disease. The most recent research suggests the average length of incubation is seven to eight years. Many people may develop AIDS sooner than this and in some instances AIDS has appeared later than this. Some people have been infected with the AIDS virus for ten years and still have no symptoms. Most AIDS researchers suspect the virus could incubate for as long as 15 to 20 years in some individuals.

Does everyone infected with the AIDS virus die?

At this point, most of the people in the U.S. who are infected with the AIDS virus are not ill. However, in studies of people who have been infected for some time, rates of illness are quite high. In one well-known San Francisco study, a group of men who are known to have been infected since 1978 or 1979 has been followed carefully. After seven years, about 75% of these men had AIDS, ARC, or lymphadenopathy (swollen lymph glands) presumed to be related to infection with the AIDS virus. As time goes on, this number is likely to grow.

These findings are startling. If they hold true in other groups, it means that most people infected will become ill. And, while it is true that some people are only mildly ill or have episodes of illness alternating with periods of health, AIDS-related infections overall appear to be progressive in nature— that is, over time the state of health deteriorates. There is a very small number of individuals who may have recovered some of their immune functioning (their immune systems have become stronger), but most people have not done so once they become ill.

The answer to this question, then, is that we do not know if everyone infected with the AIDS virus will die. We certainly hope this is not the case. Out of respect for the thousands of people living with this disease today, it seems inappropriate to make any sort of blanket statements to this effect without better evidence than we currently have.

How are people to plan pregnancies if the AIDS virus can be transmitted by semen?

If two people wish to consider pregnancy and they know confidently that neither has a past risk of exposure to the AIDS virus, they can simply proceed with their plans.

In assessing risk, one must consider (1) history of IV-drug use; (2) personal sexual history; (3) the sexual and drug use histories of any past sexual partners; and (4) any history of blood or blood product transfusion. It is difficult to know confidently about the history of past partners, and one

would want to consider experience since 1978.

If there is some doubt about the possibility of exposure to the AIDS virus, couples might consider taking the AIDS antibody test. If one or both partners have been exposed to the AIDS virus, we recommend postponing pregnancy until we have a way to prevent transmission of the virus to partners or a fetus. Donors providing semen for insemination should be tested for AIDS antibodies.

Prevention and Testing

What are the basic guidelines for adult AIDS prevention?

1. Abstain from sex; or, if you are going to engage in sexual activity, do not allow semen, vaginal secretion, blood, urine or feces of an infected person to enter your body. Use condoms for all types of intercourse.
2. If you do not know whether a sexual partner is infected with the AIDS virus, follow safer sex guidelines. Remember, you cannot tell by looking at someone whether he or she has been infected.
3. Abstain from the use of intravenous drugs. Do not share hypodermic needles or any other needles under *any* circumstances. (It is also best not to share razors or toothbrushes with an infected person because they may expose you to minute amounts of blood.)

How effective are condoms in preventing the transmission of AIDS?

Condoms have been shown to be an effective barrier to the AIDS virus in laboratory tests. When properly used, especially in conjunction with a spermicide containing nonoxynol-9, they will be an effective measure for preventing transmission of the AIDS virus. Condoms are not, however, 100% effective. Estimates of their efficacy vary, and we do not have a way to test them on a human population risking infection with the AIDS virus.

We think it is important to note that most failures of condoms to prevent pregnancy are caused by user errors. In some studies of married couples in which one partner with AIDS transmitted the virus to the other partner even though condoms were used, user error again seemed to be the most important factor—the condoms were not used in all sexual contacts, or were used for only part of some contacts. (For example, a man might have an erection, begin intercourse, then withdraw his penis and put on a condom before ejaculation. This is *not* correct use of a condom.)

If people are well educated on condom use and can use them properly, condoms will significantly lower, but not eliminate, the risk of AIDS transmission.

Are there additional ways to increase one's protection from the AIDS virus in sexual intercourse?

Spermicidal lubricants are available and can be used with condoms. Nonoxynol-9 is a substance in some of these spermicides that has been shown to kill the AIDS virus on contact. We recommend that people use a nonoxynol-9 spermicide along with a condom in vaginal and anal intercourse as "extra" insurance, in case the condom breaks. Nonoxynol-9 is *not* considered an effective preventative without a condom.

The concentration of nonoxynol-9 varies from spermicide to spermicide. To be effective, the product should carry at least 5% concentration.

Finally, any lubricant used with condoms must be *water based*, containing no fats or oils. Check labels carefully—fats and oils break down latex and cause condoms to break. Never use Vaseline or vegetable fats as lubricants with condoms.

What keeps people from following AIDS prevention guidelines?

There are different reasons people do not follow these guidelines. They may not know about AIDS prevention. They may not consider themselves

at risk. Or they may know they have a risk but believe "it could never happen to me."

Condoms are an important element of safer sex practices, and many people are embarrassed or uninformed about the purchase or use of condoms. As we redefine our concepts of sexuality and increase our comfort with safer sex, it may be easier for people to use condoms.

IV-drug users have traditionally had a difficult time changing behaviors. If sharing needles is the only way to get a drug to which you are addicted, it is very difficult to decide not to share. Drug users need AIDS prevention information, and we must redouble our efforts to prevent IV-drug addiction and abuse in the first place.

When will there be a vaccine for AIDS?

To date, a successful vaccine has never been developed for a human retrovirus, which makes finding an AIDS vaccine one of the greatest challenges for medical science so far. There is still no guarantee that a successful vaccine for AIDS can be produced, but recent developments are promising. Guesses for when a vaccine will appear run anywhere from two to ten years, and some experts believe it may never happen. Several laboratories are currently testing AIDS vaccines, but these will all need to be evaluated carefully for safety and efficacy. It will be many years at best before any vaccine can be used widely. The only course for preventing AIDS at present is to practice the AIDS prevention guidelines mentioned earlier.

When will there be a cure or treatment for AIDS and HIV infection?

Many different experimental treatments are being investigated for use with HIV infection and illness. So far none has effectively stopped or reversed the impairment of the immune system caused by HIV infection. Most drugs under investigation have significant side effects or toxicity.

Some drugs are showing positive effects, however. They may inactivate some of the virus in the body, or boost the functioning of the immune

system. Efforts are being made to develop drugs that will interfere with the ability of the virus to invade new cells, or to replicate once it has done so. We hope these studies will continue with all due speed, and that they will be generously funded so that effective treatments *can* be developed.

While we look forward to success in this area, we also acknowledge that there are many challenging problems in trying to treat or cure HIV infection. It is possible that no such treatments will appear in the foreseeable future.

What is the AIDS antibody test?

The AIDS antibody test is an inexpensive screening test that was developed to make certain blood donated for transfusions did not carry the AIDS virus. There are actually several different tests currently being used to check for AIDS antibodies, each using a different method. The most common type is an ELISA ("ELISA" refers to the method of testing used). The ELISA tells, fairly simply and quite inexpensively, whether a blood specimen has been infected with the AIDS virus. It is a practical way to screen blood donations and, because it is now universally applied in U.S. blood banks, it has made the blood supply safe. We will probably see very few future cases of the AIDS virus passed through transfusions (though people transfused before 1985 may still be at risk because of the incubation period of the disease). The test is also used to test semen donors for insemination, and it is recommended for organ donors to protect recipients of organ transplants.

Some individuals have taken the antibody test to determine whether or not they have been infected with the AIDS virus. If the antibody is *absent*, the test is *negative* and it means *one* of the following is true:

1. The person has not been infected with the virus.

OR

2. The person has had contact with the AIDS virus but has not become infected and therefore has not produced antibodies.

However, repeated exposure to the AIDS virus would increase the likelihood that the person will become infected.

OR

3. The person has been infected by the virus but has not yet produced antibodies. Research indicates most people will produce antibodies within 2-12 weeks after infection. Some people will not produce antibodies for six months or more. A very small number of people will never produce antibodies.

If the test shows that the antibody is *present,* the test is *positive,* and it means *all* of the following are true:

1. The person's blood sample has been tested and the test indicates antibodies to the virus are present.

AND

2. The person has been infected with the AIDS virus and antibodies have been produced.

AND

3. Researchers have shown that most people with AIDS antibodies have active virus in their bodies. Therefore, a person with a positive test must assume he or she is capable of passing the virus on to others under the correct circumstances for transmission.

The test is quite accurate, but like other medical tests there will be some false negatives (a person *does* have antibody, but tests negative) and false positives (a person *does not* have antibody but tests positive).

The ELISA test was developed to screen blood donations. The blood banks naturally wanted to be very careful to pull out any blood infected with the AIDS virus, so this test is more likely to err on the side of false positives (that is, it would be better to pull out noninfected blood, thereby losing a few units of blood that were actually safe), than false negatives (allowing blood that *was* infected to be used for transfusions). To correct

for this error of the test, responsible labs will usually screen blood first with the ELISA, because it is the easiest and most inexpensive test available. If the sample tests positive, they will test it two more times with the ELISA and, if both of these tests are positive, the sample will be checked again with one of the other types of tests. When these procedures are followed, results are accurate well over 99% of the time.

Unfortunately, some labs, especially some private-for-profit operations, have not been as careful as this. They will report results based on a single ELISA screening. Under these circumstances, the error rate is much higher. People wanting to take the test might want to ask about lab procedures before they do so.

Many people misunderstand the antibody test and believe it is a "test for AIDS." The test only indicates the presence of antibodies and, by association, demonstrates infection with the AIDS virus. The test does not tell whether a person has AIDS or AIDS-Related Complex (ARC) and we do not know if a person with HIV infection who feels healthy will develop AIDS or ARC.

If a person wants to take the AIDS antibody test, we recommend having the test performed where anonymity is guaranteed if possible. Anonymous testing means your name and test results are not recorded together anywhere, nor is there any record of your having taken the test. A mention of the test in medical records, even if the results are negative, might complicate future efforts to acquire health insurance. In some states a positive result could lead to legal problems.

Is the AIDS antibody test performed on children?

The AIDS antibody test can be performed on children. For newborns of infected mothers, however, the test results are complicated by the presence of maternal serum and maternal antibody in the infant's blood. This means that an infant who tests positive may *not* actually be infected with the virus, but might have antibodies from the mother's blood in its system. This situation usually resolves by the time the child is 15 months old—the mother's antibodies have cleared from the child's system. Antibody tests

after that will be about as reliable as tests on adults.

There are other considerations in antibody testing of children, however. For example, anonymous testing is not possible for young children because a parent or guardian must sign a consent form allowing the test. In addition, the consequences of a positive antibody test may be far-reaching for a child and his or her family (How will family react? What will be said to the child? Will the results become known and complicate the child's attendance at school? and so forth). We recommend strongly that parents or guardians considering testing of children receive careful counseling from a qualified medical professional familiar with the issues before any final decisions are made.

Children and AIDS

How many young children are being diagnosed with AIDS, and how have they become infected?

Children to age 12 represent about 1% of the total number of U.S. AIDS cases. In May 1988, there were 973 reported cases of pediatric AIDS. The problem is more severe than it looks from these statistics, however. Many children who are infected with the AIDS virus and showing symptoms do not meet the case definition of AIDS. This means that their cases are not reported or included in statistics. It is difficult to say how many children are ill because of HIV infection, but we can reasonably estimate the number in the U.S. to be well over 2,000 at the present time. There are probably over 5,000 additional children who are currently infected but not ill.

Today, most children are being infected perinatally—that is, their mothers are infected with the AIDS virus and pass this infection on to fetuses before they are born. Before 1985, a number of children were infected through blood transfusions or the use of blood products such as Factor VIII for hemophilia. While we should see very few new cases of infection through blood transfusions or products, the long incubation period of AIDS suggests that some children may have acquired the virus

years ago in this manner without currently being ill. We do not know how many of these children will go on to develop AIDS.

A disproportionate number of children with AIDS — nearly 80% — are Black or Latino. For most of these children, one or both parents are users of IV drugs. Often, the parents are unable to care for these children, either because of their drug habits, or because they are themselves debilitated by AIDS-related illnesses.

As child cases grow in number, they will bring a particular burden to minority communities. We must make special effort, as a nation, to provide care for these children as necessary and to support drug prevention and AIDS education programs, particularly in minority communities where these efforts have often been poorly funded and supported in the past.

Does infection with the AIDS virus affect children the same way it affects adults?

There are some important differences in how adults and children respond to AIDS virus infection. *Adults with AIDS* develop a number of unusual diseases that would not be dangerous to a healthy person, but are life-threatening to them. Generally, these individuals are not endangered by typical diseases such as colds or flu (except as they cause overall weakening). If an adult develops *Pneumocystis carinii* pneumonia, this is a clear sign that the immune system is not operating properly. AIDS can be diagnosed by the presence of this unusual disease if the individual does not have any other reason to be immune suppressed (such as having cancer, or receiving immunosuppressive therapies after surgery).

Children who are infected with the AIDS virus develop both typical and atypical diseases of childhood that are especially severe in nature and respond poorly to treatment. One of the things that makes diagnosis of AIDS difficult in children is this presence of typical diseases that many or most children have. If a child develops a bacterial pneumonia, this alone is not enough for a diagnosis of AIDS, even though it may be a symptom of the disease. Many other children will develop bacterial pneumonias and they will not have AIDS.

While adults who are infected commonly carry the AIDS virus a number of years before becoming ill, newborns who are infected are often quite ill by one year of age. This is probably because a newborn does not have a fully developed immune system and therefore has less natural resistance to the virus. It is believed that most infants born with AIDS infection have died by 18 months of age.

Among children with HIV infection, we most commonly see failure to thrive (a medical syndrome characterized by a failure to grow properly), chronic diarrhea, and bacterial pneumonias. They also will usually show neurologic problems. Rarely, children with AIDS will also have *Pneumocystis carinii* pneumonia, the most common illness found in adults with AIDS.

How serious is the threat of HIV infection of children as a result of sexual molestation?

This is a question we cannot answer with certainty. Our sense is that the likelihood of this occurring is real, but relatively small. The possibilities do seem alarming, however, when you consider the number of children who are sexually molested. In one study, 28% of the women surveyed reported being sexually abused before the age of 14. Another recent report suggested that one quarter of all abuse occurs before the age of seven. Boys are molested too. If we consider current estimates that one in three girls and about one in ten boys will be sexually molested, there is certainly a frightening potential for some of this abuse to be perpetrated by HIV-infected adults. A few such cases are known to have occurred.

We hope readers will not assume we are talking only of the possibility of HIV-infected homosexual men molesting children. While this is certainly one part of the risk, the molestation of girls by heterosexually-identified men is far more common and also concerns us greatly. We hope parents and communities will be alert to *all* cases of child molestation and the many potential risks involved.

How many HIV-infected children will actually be attending elementary school classes?

Predictions of the cumulative number of children with HIV infection expected in the U.S. by 1991 range as high as 20,000- 30,000. This is a lot of students if these children were to attend school. However, most new cases of HIV-infected children will be perinatal cases—infants born infected because their mothers were carrying the virus. At present, it does not appear that most of these children will survive to school age. This will change if effective treatments that prolong their lives are developed.

We suggest that schools prepare themselves for the possibility that HIV-infected children will be attending their schools at some point in the foreseeable future.

Most young children with HIV infection will be offspring of IV-drug-using parents. I do not think we have those kinds of children in our community.

We often think of drug users as people who hang out on the streets, living from fix to fix and supporting their habits by theft. While it is true that many addicts live this way, there are a number of people in this country who work for a living, make good money, dress nicely, speak politely, and shoot drugs. They may or may not actually be addicted.

Even people who only use IV drugs on occasion probably share needles with others at some point. They are likely to see their use as "recreational," and not consider it a problem. Since IV- drug use is an illegal activity, users are not easy to identify. Denial—of drug dependence and of AIDS risks—is common and powerful in this population.

We hope as many communities as possible will be spared the tragedy of children being diagnosed with AIDS. The risk, however, remains, even in areas that are not aware of a significant presence of IV-drug use.

What is the likelihood of an elementary student with the AIDS virus passing it on to other students (or teachers)?

Remember the means of AIDS transmission: a person must have very intimate, very direct contact with the semen, vaginal secretions, blood, or feces of an infected person. Students are unlikely to have this kind of exposure to each other in school settings. Most school-age children avoid any contact with feces. Blood may be more of a concern because of the possibility of schoolyard injuries. We believe children should be taught not to touch someone else's blood, but to call a grownup to help if someone is hurt.

Fighting or incontinence are sometimes implicated when people express their concerns about children with AIDS or HIV infection attending school. If an HIV-infected child has significant behavioral problems, neurologic or other difficulties that cause incontinence, or open sores or lesions that cannot be covered, it may be necessary to keep that child out of usual school activities. These will be exceptional cases. Most children with HIV infection will do well in a school setting, and do not pose any risk to their peers.

Teachers may occasionally need to clean up blood, urine, vomitus, etc. We believe uniform guidelines for such tasks should be set in all schools, which state the staff person (1) wears vinyl or latex gloves for such cleaning, (2) cleans the area with a 1:10 solution of bleach, and (3) washes his or her hands afterwards. This should effectively prevent transmission of HIV or other illness.

Doubts about Casual Transmission

I'm not convinced that AIDS can't be transmitted casually. There's too much we don't know about the disease.

People often have this concern, and it is understandable. AIDS is a very serious, usually fatal disease. New information about AIDS is reported at a remarkable rate. Government and civic officials discount worries about

casual transmission, but some people do not feel certain or trusting of these reassurances.

It is important to point out that we actually know a great deal about AIDS. We know it is caused by a virus and we know quite a bit about the structure of this virus. We understand how the virus attacks the immune system, and we have seen that it is fragile and dies easily outside the human body. We are familiar now with the progression of the disease and the range of illnesses that appear in infected persons. From a variety of studies, we understand that AIDS is transmitted only in circumstances where blood is exchanged, or where there is intimate contact involving the blood, semen, vaginal secretions or feces of an infected person.

This information has not changed substantially in over four years. Much of the new information reported either refines what we already understand about AIDS or addresses the issues for which we do not have answers: how to stop the progression of the disease, how to cure it, or how to vaccinate against it.

We have heard many arguments for and against casual transmission. We expect such arguments to continue, but believe that a closer look at the most common ones reinforces the scientific opinion that HIV is not casually transmitted. We review these below, along with our responses.

The incubation period for AIDS is so long. How can you be sure a lot of people who have had casual contact with persons with AIDS are not in that period of incubation? The disease could appear years from now.

The incubation period for AIDS, often five years or more, is long. However, the length of time between an infection and the development of the antibodies is fairly short, usually occurring within twelve weeks.

Many antibody studies have been performed on family members of people with AIDS who share "casual contact," and there has never been a spread of infection. Perhaps even more persuasive are the studies of health care workers who care for people with AIDS every day. Many medical personnel have been working with people with AIDS for several

years. They are often in very close contact with those infected, giving them shots, performing exams, bathing them, cleaning linen and disposing of body wastes. Simple and standard precautions are followed, like washing hands after physical examinations, wearing gloves while disposing of body wastes, etc.

An article in a July, 1987 medical journal (*Journal of Infectious Diseases*) summarized reports on over 2,400 health and dental care workers who had been tested for AIDS antibodies. Of these 817 had had either parenteral (needlestick) or mucous membrane exposure to blood or other body fluids from people with HIV infection. One worker, who was actually injected with blood which had been drawn from a person with AIDS, did become infected. Three other cases of possible work-related infection through accidental needlesticks were also reported (though other risk factors could not absolutely be ruled out in these cases).

Since this report was made, a few other instances of caregivers becoming infected have been reported. In one case a worker with chapped hands placed direct pressure on an open wound for about twenty minutes; in another, a worker had copious splashes of blood in the eyes and on open sores on the skin; and in a third, a woman caring for a sick child had regular, direct contact with the child's bloody feces and other body excretions, without the use of gloves.

The development of HIV infection in these individuals is disturbing. The greater surprise, however, is that with this many documented accidental exposures (over 800 in the journal report), we do not see more cases of infection. Almost all such cases reported so far could have been prevented if workers had followed infection control guidelines consistently. These studies further verify that AIDS is not transmitted in casual, day-to-day contact, but it may be transmitted in unusual circumstances in which there is very direct or prolonged exposure to infected blood or waste products.

We hope all health care providers will follow infection control guidelines in any patient contact in the future to maximize their chance of avoiding infection with the AIDS virus.

About 3% of AIDS cases in the United States have "no known risk factor." Where did these several hundred people get AIDS, if not through the usual risk activities reported?

Reporting on a disease diagnosed in 60,000+ modern-day Americans is a true challenge. Those affected are dispersed over the entire country, and they are treated in a variety of medical settings. Remember that 97% of people with AIDS have a known risk factor. The other 3% are entered into a category called "Undetermined," which is not actually the same as "no known risk."

The Centers for Disease Control regularly checks on cases with undetermined risks, looking for any suggestions of new modes of transmission. So far they have found none. On careful follow- up, most individuals are found to have known risk factors (such as sexual contact with an infected individual) or suspected risks (such as a history of sexual contact with prostitutes or of having sexually transmitted diseases). Here is where most of the remaining cases will fall:

1. Some people are diagnosed with AIDS and fail to return for follow-up questioning to determine risk factors. This is not uncommon among transient or highly mobile people, which many IV-drug users and some gay men are. These individuals are entered into the "Undetermined" category.
2. Some individuals are diagnosed with AIDS after death. Risk information is often unavailable in these circumstances.
3. Some people diagnosed with AIDS are too ill at the time of diagnosis to provide information about themselves. Others do not want to provide the information.
4. The major risk factors for AIDS—homosexual activity and IV-drug use—are highly stigmatized in the U.S. Many people are unable or unwilling to admit their risk activities because of this.
5. In a very few instances, individuals who do not actually have AIDS are inappropriately classified as AIDS cases. These persons may have the nonepidemic form of Kaposi's sarcoma (the

type seen before AIDS appeared), or have a sporadic case of opportunistic infection that would have occurred even in the absence of the AIDS epidemic. Such individuals are not actually HIV-infected, and therefore may have no risk history.

At the present time, AIDS cases are not categorized as resulting from heterosexual transmission unless the person can identify a sexual partner who has AIDS, HIV infection or AIDS-related risk. Since many sexually active people with multiple partners do not have full information on all their partners, there will be some cases of heterosexual transmission that are not classified as such. These cases are placed in the "Undetermined" category.

The CDC will continue to monitor "Undetermined" risk cases. Careful review of cases to date shows no evidence for any new modes of transmission, but rather continues to reinforce what we already know about AIDS transmission.

(For a full explanation of the CDC investigations, see Castro, Kenneth, et al., "Investigations of AIDS Patients With No Previously Identified Risk Factors," *Journal of the American Medical Association* 259:9 [March 4 1988]: 1338-1342.)

I know a doctor who says he/she thinks AIDS might be casually transmitted.

AIDS research is a highly specialized field, and most physicians are not AIDS specialists. They have to interpret what they hear and read just as nonphysicians do. In a 1986 survey by one magazine, a number of private practice physicians responding believed that food handlers should be tested for AIDS antibodies, presumably because they were concerned about the possibility of casual transmission.

This does not mean that there is a preponderance of scientific opinion favoring casual transmission. It means physicians, like everyone else, need careful and thorough education about AIDS risks. If you surveyed AIDS specialists who work with AIDS patients every day, you would find that they are quite confident that AIDS is not casually transmitted. You would see them following standard infection control guidelines to protect themselves

from needle sticks or prolonged unprotected exposure to blood, vomitus, urine or feces. You would also see them touch their patients, talk with them, and sometimes laugh and cry with them. These caregivers know that as long as the standard guidelines about blood and wastes are followed, there is no need for artificial barriers to human caring and understanding.

We understand that doubts about casual transmission will continue for some people. Given the serious nature of the disease, this is understandable. We think a look at the scientific evidence shows very persuasively that AIDS is not transmitted without the intimate exchange of blood, semen, vaginal secretions or waste products. In all cases reported thus far, there is *no* case that has been shown to be transmitted through saliva, sweat, tears or any casual contact. If you personally continue to question the transmission of AIDS, we encourage you to ask further questions of AIDS information resources (see *Further Resources*).

Conclusion

People often worry that they do not have enough information to talk to children or teens about AIDS, or that they cannot keep up with all the new information that is constantly being reported. We hope this chapter has given you a better understanding of AIDS facts. We also want to remind you that the most basic AIDS information concerning transmission and prevention has not changed in many years. This includes: (1) AIDS is not casually transmitted, (2) specific behaviors put people at risk (namely, the sharing of needles for IV-drug or other uses, or having unprotected sexual intercourse with an infected partner); and (3) avoiding these practices will protect you from AIDS infection.

You can always check with an AIDS information hotline for further information. Some national lines are listed in the *Further Resources* section of this book. The next chapter also discusses how to stay updated on AIDS information.

This chapter was adapted from *Teaching AIDS: A Resource Guide on Acquired Immune Deficiency Syndrome* (Revised edition) by Marcia Quackenbush and Pamela Sargent. Santa Cruz, CA: Network Publications, 1988.

Chapter 11

Staying Updated on AIDS Information

News about AIDS is always being reported, and often there is a sense that we cannot possibly keep up with all the current knowledge. Many teachers and parents (as well as AIDS educators) wonder how well they can teach children about AIDS when things change so quickly. It is impressive to consider that in 1981, when the disease was first recognized and described, we did not even know what the cause was. Today, we understand how AIDS is transmitted, we have identified the virus that causes it, we know how to prevent it, and a good screening test has been developed to protect the blood supply.

We will continue to discover new information about AIDS, but it is important to remember that the most essential knowledge to teach young children has not changed in many years. AIDS is still a serious disease, it primarily affects adults, and scientists are working hard to discover how to stop the spread of the disease and cure those affected.

If we consider the more sophisticated questions some children may have about AIDS transmission and prevention, we see that this information has also remained the same. The modes of transmission described in 1983—sexual intercourse, blood exchange through needle use or other means, and perinatal transmission from mother to fetus—are the only known means of transmission many years and tens of thousands of cases later. Prevention strategies—sexual abstinence, mutual monogamy or the practice of safer sex techniques with

sexual partners; and abstinence from IV-drug use or not sharing needles—are not any different today than they were five years ago. The risks for young children overall continue to be very small (except for newborns of IV-drug using parents), and our main task when young children express concerns about AIDS is to reassure them that they are not at risk of exposure in their usual day-to-day behaviors.

For this most basic education for young children, neither parents nor teachers need to make any unusual or heroic effort to keep up-to-date on the most recent scientific advances in AIDS research. Major changes in information about AIDS as well as updates on the numbers of cases recorded are usually reported in newspapers and news magazines. Regular reading of these sources should keep parents and teachers adequately informed. There is a list of AIDS information organizations in the *Further Resources* section of this book. You can check these sources for current information or to ask any questions that arise. As children grow and mature, somewhat more effort may be needed in this regard. We would recommend that teachers of older elementary, middle and high school students be updated regularly on AIDS information through inservice trainings, newsletters, school bulletins, professional journals, and so forth.

Chapter 12

AIDS Information and Developmental Stages: What Do Children Want to Know About AIDS, When?

As children grow and mature and they face new experiences, different kinds of questions and concerns about AIDS will naturally arise. A child who has just turned two is unlikely to have worries about AIDS under any circumstances. A five year old may be quite disinterested in the matter until overhearing a television program or adult conversation in which AIDS is mentioned, then suddenly express great curiosity or concern. A sophisticated ten year old may have a thorough understanding of AIDS transmission and prevention.

In this chapter, we review typical issues related to AIDS education by age group, and make general suggestions about how to respond to children's questions and needs. *Remember that developmental guidelines are always generalizations, and individual children will vary.* Many different elements affect children's development, among them region (in what part of the country does the child live?), race and ethnicity, language history (is the child being raised in a bilingual family? does the child speak a language at home different than the language used at school?), socioeconomic status, culture, and individual personality.

To set the necessary foundation to educate children well about AIDS, we suggest several overall goals, including (1) to promote self-esteem and positive self-image, confidence and self-determination for the child; (2) to teach the value of health and the idea that personal effort is required to protect one's own

health; (3) to inform about the basics of human sexuality, drug use and AIDS to the extent that this is relevant and appropriate; (4) to help children understand the nature of human intimacy and the range of human relationships, again at levels appropriate for the child; (5) to provide children with skills necessary to protect them from AIDS-related risks; and (6) to help children develop a sense of belonging and commitment to their communities, and to feel compassion for people affected by the AIDS epidemic.

Infants (birth to 11 months)

The infant is extremely egocentric and self-involved, relating to other people and the environment primarily in terms of his or her own bodily comfort. Body sensations are the major way the infant experiences the world, and this earliest period is a very sensual one. Constant and loving physical touch is essential to the child's healthy development. Bonds to the family are established, and the major emotional task of the infant is to learn to trust that caretakers will provide a safe and comfortable environment. Infants smile, laugh, cry, establish and hold eye contact, and generally enjoy social attention and people. Boys experience penile erections and girls experience clitoral erections and vaginal lubrication. Most infants, as they develop the necessary muscle coordination, engage in some genital touching and stimulation during bath or other times diapers are removed.

At this stage, children obviously are not asking questions about AIDS or anything else. But in these earliest months of a child's life, the parents are offering important lessons about self-concept and body sensation. If parents restrict children from genital touching, the child understands that genitals are disapproved of. If a child has a chaotic or difficult environment with irregular and unreliable care, he or she cannot learn to trust in caretakers. Without this essential early trust experience, later development of self-trust and self-confidence is difficult. The older child (and teen) with low self-esteem and poor self-concept will not be able to care effectively for personal health and well-being.

A loving, nurturing and accepting environment for an infant lays a foundation for later success in understanding and coping with these issues.

Toddlers

Young toddlers (one year olds) continue to be quite egocentric, but begin for the first time to have a sense of themselves as separate from others. Speech begins and communication skills improve. This child delights in the magical effects of language—if the child says "Hi" to someone, that person often responds! Early toddlers usually express many emotions—jealousy, anger, love and attachment. They are intensely interested in the surrounding environment, are active and curious, and explore anything they can get into. Attention shifts rapidly. Play activities are solitary, though the child enjoys watching others at play, work or other pastimes.

Older toddlers (two year olds) are able to focus a bit more, though the attention span is still short. There is a greater sense of individuality and separateness. Self-concept and self-esteem begin to develop, based on the appraisal of the parents and other significant adults in the child's life.

The two year old experiments with limits and boundaries— running away from caretakers, disobeying, being negative. He or she also likes to affect the physical environment. However, in these investigations and statements of independence, the child comes face-to-face with family rules and the demands of social conformity. He or she learns that independence and freedom are possible only when certain conventions are followed. While the child does not truly understand right from wrong, he or she does respond to consistently applied limits.

Rituals and routines of behavior are very important. Early health practices regarding grooming, bathing and eating are established. Toilet training is accomplished.

Children this age like to help out with tasks and love to do things for themselves. Family relations interest them, and they may act out family experiences in play with other children. If they have fears, these will tend to be of things like giants, monsters or the dark.

Parents and caretakers of both younger and older toddlers can continue providing the loving and secure environment the child needs while beginning to set routines and family rules. As the child grows and develops, the list of routines and rules will lengthen. By promoting (and sometimes enforcing) hygiene practices—brushing teeth, bathing, combing hair—parents teach children that good health is important and it takes some effort to protect it.

The child is learning about intimacy and family relationships. He or she feels differently towards mother and father than a stranger, for example. Behavior allowed with immediate family may differ from behavior accepted around visitors. While this may seem a long way from the complexities of intimate adult sexual relationships, it is this very basic level of understanding that provides a foundation for children to expand on as they mature.

Children also learn names of body parts during this period. Using correct names for genitals (penis, testicles, vagina, vulva, clitoris, urethra) teaches children that there is no shame associated with having genitals. This is one of the earliest and most positive sexuality education tasks of parents.

Toddlers do not understand concepts of past, present or future, nor do they have the tools necessary to conceptualize the passage of time.

Children this age may pick up slang words describing sexual practices or excretory functions, or they may repeat the word "AIDS" if they have heard it somewhere. If adults act startled or upset at these times, the child may repeat the words because he or she enjoys watching this reaction. A neutral response from adults will send the child in search of different, more exciting words to use. There is no particular meaning for a two year old in such language. AIDS is well beyond this child's comprehension.

Early Childhood

Three years: Three year olds develop more amenable social skills. They enjoy being affectionate with other children and adults, are often friendly and agreeable, learn to share toys and enjoy being with their peers. Like their younger counterparts, they experience powerful emotions, but they are learning skills of self-control and restraint, which help them cope with these feelings more effectively. Sibling rivalry becomes apparent at this age.

By three years, children can understand the anatomical differences between the sexes and are reassured by positive, basic explanations of the normalcy and health of both girls' and boys' genitalia. There may be some display of sexual organs in play with other children and removing of clothes outdoors. These children are curious about the different postures boys and girls use for urinating, and girls will often try to urinate standing up.

Three year olds are also interested in babies and like to see and be around infants. Questions about where babies come from may first arise at this age.

Parental attentions can continue to teach the three year old self-confidence, norms of social behavior and adherence to rules. At this age, as children socialize more with peers, they also share sexual information with one another. Parents who have been careful and factual in their sexuality education and terminology may be surprised by some of the ideas and words their children come home with. Ongoing dialogue and willingness to answer questions becomes important, and will continue to be important throughout the child's development to adulthood. Where caretakers see or hear obvious sexual misinformation, they may wish to bring up the topic and correct misunderstandings. There will continue to be a fair amount of interest in anatomy and conception, and many opportunities for discussion will usually arise.

Three year olds may develop some interest in death if a pet dies or as they come across dead animals or bugs in their outdoor explorations. They cannot understand the full meaning of death, or its permanence. They often expect dead beings to "wake up again" and get on with the things they normally do—"The bird has flown back to the sky now," they might say, ignoring the decomposing corpse on the ground nearby. Health and well-being are abstract concepts that will not make much sense to a three year old, but caretakers can use such concepts in talking about hygiene and health habits, and the child will "grow" into them ("I want you to eat more of your vegetables before you eat your cookie. You need lots of 'grow food' to stay healthy.") Mild illness will not stop this child, though moderate or severe illness is certainly noted. Illness in others is not especially important except if it might affect the child quite directly—"Your mother is sick and trying to sleep. Please be quiet and don't disturb her." Three year olds will not be interested in AIDS.

Four years: Four year olds continue to be fairly cooperative, though they are also selfish and impatient. They play imaginative games with peers and may have a make-believe playmate. They enjoy the companionship of children more than adults, while continuing to develop strong feelings of love and attachment to their family and home. They talk openly with others about family events, including things parents would prefer to keep private!

This child is proud of accomplishments, enjoys praise, and is sensitive to blame. He or she likes to brag and boast, is beginning to understand concepts of "good" and "bad," and has the capacity for some self-criticism. "Privacy" can

be explained to the child, and rules about respecting others' privacy can be followed. Four year olds also enjoy having some privacy of their own and can be taught about personal activities that are best carried out privately (for example, toileting or masturbation).

The four year old is clear about and wants to state his or her gender identity: "I am a girl and you are a boy." There is interest in human bodies generally, especially how males and females are different, what the parts of the body usually covered by clothes look like, how adults differ from children and whether children will look like their parents when they grow up. Questions about the origins of babies will continue, including how a baby gets out of its mother's "stomach."

The four year old continues to benefit from parental love and guidance, and the willingness of caretakers to answer questions about people, sexuality and reproduction. A mature four year old with a reasonable foundation of knowledge about the anatomical differences between males and females is capable of understanding a simple explanation of intercourse. Some children will ask these kinds of questions, others will not. Some children this age may ask about AIDS, but most will not. For most four year olds, health will continue to be an abstract and not especially relevant concept, though there is interest in *healing*, especially if a wound requires the attention of a bandage. Concepts about death continue to be vague, with little understanding of either a biologic or spiritual meaning of death.

The four year old is knowledgeable about family rules and generally follows them, but may not have a clear understanding of the basis for the rules. Self-care and self-protection are still practiced primarily out of habit and to accommodate adults. These children understand that they are not to cross the street without holding a grown-up's hand, or go anywhere with strangers.

Adults may carry on conversations while children pursue other pastimes nearby and appear not to be listening. In fact, children often *do* listen carefully to these grown-up discussions. By age four, they will be learning a great deal from "overheard" conversations. Parents especially can take advantage of this by pursuing discussions that will contribute appropriately to a child's knowledge and sense of well-being, whether this be about health generally, human sexuality or other relevant topics. Such conversations can serve as a reinforce-

ment of earlier discussions with a child, or might help set some basis for future talk.

School Age

Five years: Beginning school is an important transition for children and their families. While many children attend day-care and preschool facilities, most will find themselves in the less intimate and more structured setting of public school around age five. A whole new realm of influence and experience enter both the child's and the family's life.

Many five year olds talk constantly and are interested in everything. They are more attentive to their surroundings and hear things they might have ignored when they were younger. They bring home new words, new concepts and challenging questions which may startle or baffle parents. Often these have to do with human sexuality. It is an exciting, rewarding and sometimes difficult time for all.

The five year old is blossoming in social skills. He or she wants to please parents, teachers and other important adults, likes to make friends, and is learning more about leadership, giving and receiving, and social convention. This child is protective of younger children and concerned about the welfare of others. He or she spends more time with playmates than with family, and is increasingly more autonomous. There is tremendous motivation to grow up, be as big as parents, or act like older kids.

Five year olds are fairly independent in most of their health and grooming routines, and they generally understand and follow safety rules well. At this age, children seem to have limitless energy. They enjoy showing off their vigor, strength and health. Mild illness will hardly slow them—they are frustrated by grown-ups' attempts to calm them down when they run a temperature or have a cough.

Many concerns relevant to AIDS are of interest to the five year old: conception, birth, marriage, death, sexuality and all kinds of human relationships. Fears are often much more specific than for the younger child. Five year olds fear things like violent death, kidnapers and criminals. Fears of fatal diseases or AIDS specifically may arise for some five year olds. The concept of health as a state of strength and energy is willingly accepted. In his or her attempt

to catch up with adults, the five year old may well pronounce, "I am strong and healthy and powerful!" Germs are attributed as the cause of many diseases, though there may be genuine confusion about what germs really are, what they look like and where they hide. This child understands that colds and flu can be passed by kissing or sharing cups. Rules, which were once followed from blind obedience, may now be followed because they are rational and useful.

With a five year old, parents, caretakers and teachers will have many opportunities to teach about family relationships, other human relationships, health practices, community responsibilities and sexuality. Human reproduction, simply explained, is understood by most five year olds (though they may forget correct explanations and continue with fantasy ideas of babies being manufactured or bought in stores). With this knowledge in place, HIV transmission can be comfortably and appropriately explained to a five year old if necessary. ("Remember how we have talked about how some grown-ups have sexual intercourse? Some illnesses can be passed from one person to another person when people have sexual intercourse. AIDS can be passed this way.")

At this age, questions about AIDS are more likely to arise than before. Children may pursue detailed answers by asking more and more specific questions. This is typical of how five year olds learn—from the general to the specific—and they will do this with any topic of interest.

Six years: The six year old continues with many of the same interests as the five year old. As cognitive skills develop, the six year old is able to handle a wider variety of information at more sophisticated levels. The younger child was interested in events and experiences primarily as they related to him or her personally. The six year old begins to be interested in the experiences of others and to have some empathic awareness even if not directly affected by an event.

Questions about sexuality will continue to be asked at home if the child has felt comfortable doing so thus far. Parents are sometimes surprised to find issues they thought were adequately explained in the past coming up again. Young children tend to remember this information selectively, however, and even very bright children may need explanations repeated several times during this period of their lives.

Children are also aware of other resources for sex information and will certainly explore these avenues as well— peers at school, older siblings, or

older students carry a wealth of sexual information of wildly variable accuracy. Television programs or popular music may be suggestive without being thorough. There may be significant confusion about sexual issues.

Some six year olds have developed cognitive skills that allow new kinds of abstraction in thinking about human relationships and life and death. It is around this age that some children will first be able to see that death is a final, irreversible process. There may be further interest in the spiritual implications of life and death.

As the child grows and social contacts in school and other settings expand, there will be increasing likelihood that he or she will hear information about AIDS. A common misconception at this time is that people get AIDS from being bad. Many other beliefs may be inaccurate or magical, and they may change with some frequency.

Seven and eight years: The seven or eight year old continues the trend of growing sophistication in understanding the world, and growing autonomy and independence. Increasingly more time is spent with peers and away from family, and there may be tremendous exposure to television programs, movies and videos full of intriguing information about sexuality, violence and death. Around this age, boys and girls will divide into separate groups on the playground.

These children have longer attention spans; a good orientation to past, present, and future; an understanding of ways of measuring time; and a better ability to remember information after one or two explanations. They are more likely to be able to comprehend death as a permanent event, though this may be complicated by the constant resurrections of dead characters in televisions and videos. They can understand more complicated human relationships, and are themselves beginning to engage in some of the greater complexities of human interaction—they may have a best friend, they may compete with others for the friendship of a popular child, there will usually be particular children they clearly dislike, and they may be hurt deeply in conflicts with their peers.

Interest in sexual matters continues. For some children, there will be more emphasis now on sexual feelings than on curiosity about reproduction. Beginning at birth, children have sexual feelings of their own, and by age seven or eight they may make the connection between what they are feeling and what

everyone else is talking about. This is also a time when children who have been open with their parents about their sexual questions in the past might become more private, embarrassed or withdrawn.

Interest in matters other than sexuality continues as well. World events, nuclear arms, poverty, drug use, war and violence all enter the awareness of young children. Questions are raised and anxieties may be expressed when major events or personal experiences bring these kinds of concerns closer to the child's own life. Stories about children with AIDS who have been mistreated may be especially interesting and/or disturbing to these children. Given an opportunity to discuss AIDS with a trustworthy adult, children this age may have many questions, usually over a much broader range of concerns than the five or six year old.

Parents and teachers can offer informative answers to children's questions, and in addition may also seek to impart skills to help children cope with this increasingly difficult information and keep it in healthy perspective in their lives.

Nine and ten years: Nine and ten year olds stand on the threshold of adolescence. Differences in cognitive, social and emotional development, so evident throughout the childhood years, become even more pronounced at this time. Some of these children continue to think and act very concretely, to play children's games, and to enjoy a lot of intimacy with their families. Others are really more like early adolescents, paying attention to styles of dress, dance and music, and spending very little time at play. They may distance themselves more from their families, sometimes having conflicts with parents concerning behavior or values.

Reading becomes an important activity for many children this age. They can involve themselves in full novels, thereby bringing a new dimension to their knowledge of the world. They are able to escape the people and places around them without ever leaving their chairs.

Nine and ten year olds have a better cognitive understanding of cause-and-effect relationships, and are usually capable of understanding a fuller range of human activities as well. They are more tolerant of ambiguity and less insistent on black-and-white solutions, though they still feel most comfortable with concrete answers to questions and problems. Complicated statements and

relationships make more sense—this child is much better able to understand, for example, that AIDS can be transmitted several different ways.

Ten year olds are quite able to understand that there is a variety of human sexual activities, that there are consequences to sexual behavior (unwanted pregnancy, sexually transmitted disease, emotional difficulties), and that it is a good idea to delay intercourse. It will be important for these children to understand the dangers of AIDS, how it is transmitted and how to prevent transmission. They will develop a much more sophisticated understanding of drug abuse problems. In some areas, nine and ten year olds will know older children who are already using substances. It is during these years that many children will have their first real-life practice in turning down offers to use drugs or be sexually active.

These are essential years for parents and other adults to be actively involved with children, to talk with them regularly, to be available to discuss problems and concerns, and to help them strengthen their own sense of self-worth and self-esteem. It is particularly important that children at this age be prepared with sound information and strong personal support to face the increasingly adult demands that await them.

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Ideally, families of children six to ten years old will have regular and ongoing discussions about a whole range of sensitive issues, including human sexuality, personal morality and values. Parents are the most influential teachers of values to children, whether or not they pursue this task deliberately. Children learn from their parents what sorts of values to place on friendships, human beings generally, family and community responsibilities, work, the status of women, the importance of love and intimacy and appropriate roles for children and adults.

Young children love to talk about deep issues (usually for brief periods of time) and to be taken seriously. Questions about AIDS and other issues may be searching and thoughtful in these years. Concern for the welfare of others and interest in community values grows. When adults carry on these conversations so that the child understands the content and feels respected, the child is able to develop essential qualities of self-worth and self-confidence.

Classroom teachers can offer structured lessons in health, disease, and how to prevent illness; drug abuse prevention; healthy behaviors concerning diet, sleep and exercise; and different types of human relationships. Children can be helped to develop skills in asking questions and getting answers about things of interest to them. Child sexual abuse prevention programs should be available for first graders and older children. Drug prevention programs are also appropriate at this age, and the role of IV-drug use in the spread of disease (including AIDS) can be understood. If a particular school or district has a family life education program, this will further help teachers and parents in discussing many of the concerns that arise for young children, including concerns about AIDS.

The most important thing to keep in mind as you think about talking about AIDS or other sensitive issues with children is that, while it is a challenging task, it is not difficult when a foundation of knowledge and openness is already set. If an eight year old with no familiarity with human sexuality, health practices or communicable disease asks, "How do people get AIDS?", the answer will be complicated, long and probably confusing for the child. You would need to cover what AIDS is, something about how diseases are passed generally, human sexual practices, the possibility of AIDS or other diseases being passed sexually, IV-drug use, and the role of IV drugs in AIDS transmission. However, if you have already been talking about these general topics with a child even as young as five, the answer is fairly simple (you can read our example in Chapter 4: *What Are Children Asking, and How Can You Answer Them?).*

Chapter 13

Signs of Child Sexual Abuse

Discussions about AIDS may raise particular anxieties for children who have been abused sexually. There are a number of physical and behavioral clues that suggest a child may be a victim of sexual abuse. We include a list of these here to remind parents, teachers and others who provide care to children to always be alert to this possibility.

If you have clear evidence that a child is being abused, we urge you to act swiftly to inform the necessary authorities and see that the child is protected. If you suspect such abuse may be occurring but you are not certain, your local child protective agency will be able to provide you with further advisement. Anonymous calls to these agencies are always possible. You will find them listed in the phone book under "City and County Services." You can also get further information from your local police department.

Indicators of Sexual Abuse in Children*

The following physical and behavioral characteristics may be signaling that a child is a victim of sexual abuse. As with other lists of symptoms, some of the same signs may indicate other types of problems. Until recently, sexual abuse was not often considered as a possible reason for erratic or problem behavior.

It is important to recognize that sexual abuse is a possibility when a child/adolescent exhibits several of the following behaviors.

Physical Signs

Bruising, bleeding or infections in the genital/anal area. Physical symptoms may be manifested as difficulty in walking, sitting or urinating; scratching or tugging at clothing around the genital area; torn, stained or bloody clothing; genito-urinary complaints or infections.

There may be no physical indicators that a child is being abused.

Behavioral/Attitudinal Signs

- Eating, sleeping and eliminating disturbances
- Recurrent physical complaints
- Withdrawn or aggressive behavior
- Tired, lethargic, sleepy appearance
- Fearful or suspicious of adults
- Sexually explicit language or behavior not appropriate to the child's age
- Regressive behavior such as whining, excessive crying, thumbsucking, wetting or soiling self
- Aversion to a particular person, place or situation
- Change in school performance, truancy
- Fear, worry, overly serious, depressed
- Anger toward or dislike of adults, authority figures
- Running away from home
- Suicide threats or attempts
- Behavioral defiance, sexual promiscuity, prostitution
- Shy, withdrawn, overburdened appearance
- Substance abuse that is more than experimental
- Reluctance to undress for physical education
- Stealing, shoplifting
- Pregnancy wishes
- Interest in early marriage
- Attraction to older men or dislike of men
- Excessive hand washing, bathing

- Unreasonably restricted social activities or overly protective father
- Poor self-image, low self-esteem
- Fantasies about victimization or violence
- Alienation from family members, rejection of typical family affection
- Fear of strange men and/or strange situations
- Fear of being alone
- Overly clinging or dependent behavior
- Extreme avoidance of touch
- Abrupt change in behavior or personality
- Extreme over-achiever

*Reprinted from *The Educator's Guide to Preventing Child Sexual Abuse*, edited by Mary Nelson and Kay Clark. Network Publications, a division of ETR Associates, Santa Cruz, CA, 1986.

SECTION 3

FURTHER RESOURCES

Appendix A

Readings

General AIDS Information

AIDS Project Los Angeles. *AIDS: A Self-Care Manual.* Los Angeles: AIDS Project, Los Angeles, 1987.

Frumkin, Lyn Robert and John Leonard. *Questions and Answers on AIDS.* New York: Avon Books, 1987.

Hatcher, Robert, James Curran and Susan Lloyd Schulz. *The AIDS Answer Book.* Santa Cruz, CA: Network Publications, forthcoming.

Institute of Medicine and National Academy of Sciences. *Confronting AIDS: Directions for Public Health, Health Care and Research.* Washington, DC: National Academy Press, 1986. Revised 1988.

Jennings, Chris. *Understanding and Preventing AIDS.* Cambridge, MA: Health Alert Press, 1988.

Koop, C.E. *Surgeon General's Report on Acquired Immune Deficiency Syndrome.* Washington, DC: U.S. Department of Health and Human Services, 1986.

Norwood, Chris. *Advice for Life.* New York: Pantheon Books, 1987.

Peabody, Barbara. *The Screaming Room.* San Diego, CA: Oak Tree Publications, Inc., 1986.

Child Development/Parenting

Boston Women's Health Book Collective. *Ourselves and Our Children: A Book By and For Parents.* New York: Random House, 1978.

Caplan, Frank. *The First Twelve Months of Life.* New York: Bantam Books, 1985.

Caplan, Frank and Theresa Caplan. *The Second Twelve Months of Life.* New York: Bantam Books, 1985.

Caplan, Theresa and Frank Caplan. *The Early Childhood Years: The 2 to 6 Year Old.* New York: Bantam Books, 1984.

Parent/Child Sex Education

Calderone, Mary and James Ramey. *Talking With Your Child About Sex: Questions and Answers for Children from Birth to Puberty.* New York: Ballentine Books, 1982.

Planned Parenthood Federation of America. *How to Talk With Your Child About Sexuality.* Garden City, NY: Doubleday & Company, 1986.

Children's Attitudes Towards Chronic Illness and Death

Krementz, Jill. *How It Feels When A Parent Dies.* New York: Alfred A. Knopf, 1988.

Rando, Therese. *Grief, Dying and Death: Clinical Interventions for Caregivers.* Champaign, Illinois: Research Press Company, 1984. [Especially Chapter 12—"The Family of the Dying Patient," and Chapter 13—"The Dying Child."]

Stein, Sara Bonnett. *About Dying: An Open Family Book for Parents and Children Together.* New York: Walker and Company, 1974.

The Center for Attitudinal Healing. *There is a Rainbow Behind Every Dark Cloud.* Millbrae, California: Celestial Arts, 1979.

Family Life Education Curricula for Elementary School Settings

Brown, Jean et al. *Sexuality Education: A Curriculum for Parent/Child Programs.* Santa Cruz, CA: Network Publications, 1984.

DeSpelder, Lynne and Albert Strickland. *Family Life Education: Resources for the Elementary Classroom, Grades 4, 5 and 6.* Santa Cruz, CA: Network Publications, 1982.

Comprehensive Health Education Materials

American Health Foundation. *Know Your Body.* New York: American Health Foundation, 1980.

National Center for Health Education. *Growing Healthy, K-6.* New York: National Center for Health Education, 1986.

Pollock, Marion B. and Kathleen Middleton. *Elementary School Health Instruction.* St. Louis: Times Mirror/Mosby, 1984 (second edition forthcoming).

Preventing Child Sexual Abuse

Nelson, Mary and Kay Clark, eds. *The Educator's Guide to Preventing Child Sexual Abuse.* Santa Cruz, CA: Network Publications, 1986.

Preventing Drug Abuse

Comprehensive Health Education Foundation. *Here's Looking At You 2000.* Seattle, WA: Comprehensive Health Education, 1986.

AIDS and Schools

Centers for Disease Control. "Guidelines for Effective School Health Education To Prevent The Spread of AIDS." *Morbidity and Mortality Weekly Report* 1988;37 (suppl. no. S-2). Atlanta, GA: Centers for Disease Control, 1988.

Hooper, S. and G. Gregory. *AIDS and the Public Schools.* Alexandria, VA: National School Boards Association, 1986.

Quackenbush, Marcia, Mary Nelson and Kay Clark, eds. *The AIDS Challenge: Prevention Education for Young People.* Santa Cruz, CA: Network Publications, 1988.

Appendix B

Information Sources

The network of AIDS information and service resources is large. There are organizations or agencies responsible for coordinating AIDS services in every state. The national information number, listed below, maintains up-to-date listings of local resources throughout the country. Not all of these organizations have information hotlines.

Hotlines

National AIDS Hotline
(800) 342-AIDS - Toll free
(202) 245-6867 - Collect from Alaska and Hawaii
Administered by the Social Health Association

National Gay Task Force
AIDS Information Hotline
(800) 221-7044
(212) 807-6016 (NY State)

STD National Hotline
(800) 227-8922
Administered by the American Social Health Association

Written Resources: Pamphlets, Brochures, Posters

Call or write for description of materials and price list. Some of these agencies will also provide speakers for school assemblies, consultation for teachers or education for parents.

California

AIDS Project, Los Angeles
1362 Santa Monica Blvd.
Los Angeles, CA 90046
(213) 876-AIDS

Network Publications
A Division of ETR Associates
P.O. Box 1830
Santa Cruz, CA 95061-1830
(408) 438-4080

San Francisco AIDS Foundation
P.O. Box 6182
San Francisco, CA 94101-6182
(415) 864-4376

Maryland

Health Education and Resource Organization (HERO)
101 West Read St., Suite 812
Baltimore, MD 21201
(301) 685-1180

Massachusetts

AIDS Action Committee
661 Boylston St.
Boston, MA 02116
(617) 536-7733

New York

Gay Men's Health Crisis, Inc.
132 West 24th St.
New York, NY 10011
(212) 807-6655

Hispanic AIDS Forum
140 West 22nd St., Suite 301
New York, NY 10011
(212) 463-8264

North Carolina

American Social Health Association
P.O. Box 13827
Research Triangle Park, NC 27709
(919) 361-2742

Washington, DC

American Red Cross
AIDS Education Office
1730 D St., NW
Washington, DC 20006
(202) 737-8300
or contact local Red Cross

National AIDS Network
1012 14th St. NW, Suite 601
Washington, DC 20005
(202) 347-0390

U.S. Public Health Service
Public Affairs Office
Hubert H. Humphrey Building , Room 725-H
200 Independence Ave., SW
Washington, DC 20201
(202) 245-6867

About the Authors

Marcia Quackenbush, MS, is Coordinator of Youth and Women's Services for the AIDS Health Project, a program of the University of California, San Francisco, and the San Francisco Department of Public Health. She has been active in AIDS prevention education for youth since early 1984. She has trained teachers and other educators on AIDS prevention approaches with children and youth, and is coauthor of *Teaching AIDS,* a resource guide for secondary teachers. In her role as an advocate for AIDS education, she has appeared on national television, spoken on radio shows across the country, and testified before a Congressional Committee. She counsels persons with AIDS, ARC and HIV infection.

Sylvia F. Villarreal, MD, is Assistant Clinical Professor of Pediatrics and a staff member of the Children's Health Center at San Francisco General Hospital. She is Director of the Kempe High Risk Clinic and Early Childhood Services. Her community work includes membership on the San Francisco Department of Public Health AIDS Minority Task Force as well as the Department of Public Health's Refugee Task Force and the Community Forum for Children and Youth for the City of San Francisco. She is a member of the board of directors for the California Children's Lobby. Dr. Villarreal has published extensively on health care issues and her field of research is nonorganic failure to thrive.

How much do children need to know about AIDS? How should adults respond to their questions about AIDS, and what are they likely to be? People often worry that they do not have enough information to talk to children about AIDS, or that they cannot keep up with all the news. *"Does AIDS Hurt?"* gives teachers, parents and others who spend time with young children basic information and suggested guidelines for addressing the real issues.

This practical resource, written by authors sensitive to the developmental needs of young children, emphasizes the use of age-appropriate responses to children's questions. Maintaining that children do not need explicit information about AIDS, *"Does AIDS Hurt?"* underscores the importance of a solid general health education in giving children the tools to understand concepts about disease transmission. Classroom examples demonstrate effective ways of providing relevant and appropriate AIDS education to young students.

Additionally, *"Does AIDS Hurt?"* covers:

- When to bring up the topic of AIDS
- Trouble shooting: anticipating problems that might arise in discussing AIDS with young children
- Special circumstances: when a child, family or friends are at risk for or infected with HIV
- The school with HIV-infected students or staff
- Staying updated on AIDS information

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